

Telling tales:
the development and impact of digital
stories and digital storytelling in
healthcare

Victoria (Pip) Hardy

PhD

2016

Telling tales:
the development and impact of digital
stories and digital storytelling in
healthcare

Victoria (Pip) Hardy

A thesis submitted in partial fulfilment of
the requirements of the
Manchester Metropolitan University
for the degree of Doctor of Philosophy by
Published Work (Route 1)

Faculty of Health, Psychology
and Social Care

2016

Acknowledgements

I am grateful to all the storytellers, without whose courage, honesty and generosity the Patient Voices Programme would not exist; to all the people whose vision has led them to sponsor workshops in which the digital stories have been created, and those who have used the stories in so many creative and thoughtful ways to inspire learning and change.

Thanks are also due to the many friends and colleagues I have had the good fortune to meet through my work with Patient Voices and in the wider world of digital storytelling.

Many thanks also to Manchester Metropolitan University for enabling me to complete this PhD via a funded studentship.

I am more grateful than I can say to my supervisor, Carol Haigh, for her encouragement to do a PhD in the first place, her helpful support along the way, her belief that I could do it (even when all appearances were to the contrary) and that it would be good enough, her clever wit and amusing conversations, her sympathy when it was needed, her endless patience and, most importantly, her enduring friendship.

No work on digital storytelling would be complete without acknowledging the enormous debt to StoryCenter (formerly The Center for Digital Storytelling) and especially to Joe Lambert who, along with the late Dana Atchley, held the very first digital storytelling workshop and has continued to work tirelessly and listen deeply to anyone and everyone with a story to tell.

And, last but not least, grateful thanks to Tony Sumner, the other half of Patient Voices, without whom none of this would ever have happened.

Abstract

Since its inception in 2003, the Patient Voices Programme has been gathering and disseminating digital stories of healthcare created by patients, carers and clinicians involved in delivering and receiving that care. It is one of the longest-running digital storytelling projects in the world and, as far as can be determined, the only digital storytelling project to focus specifically on healthcare. During this time, more than 1000 digital stories have been created. Once released by storytellers, these stories are made freely available by a publicly accessible website for use in healthcare education and service improvement programmes. The aim of Patient Voices was, through sharing the stories of what really matters to the people who design, deliver and receive healthcare, to bring about a transformation, resulting in safer, higher quality care characterised by greater humanity and compassion.

I am one of the founders of the Patient Voices Programme. I have played a key role in every aspect of the Programme's development, from working with the first storytellers and writing the original rationale, to conducting research on the impact of the stories, presenting at numerous conferences, writing papers for publication, facilitating workshops and consulting on use of the stories.

Not only has the Patient Voices Programme had an impact on the world of healthcare, particularly in the UK, but it has also had an impact on the wider world of digital storytelling, where the Patient Voices Programme is regarded as the world leader in digital storytelling in healthcare; indeed, I have given a keynote address at four of the last five international digital storytelling conferences.

Through an examination of eight published papers and the Patient Voices website, this thesis will demonstrate the contribution that I have made, through the Patient Voices Programme, to healthcare and healthcare education as well as to the wider, emerging field of digital storytelling.

Contents

Acknowledgements.....	5
Abstract.....	6
Contents.....	7
Chapter 1: Introduction.....	1
1.1 Background	1
1.2 Aims of the thesis	2
1.3 Structure of the thesis.....	3
1.4 List of publications to be included in the thesis	3
References	4
Chapter 2: A history of digital storytelling in healthcare	5
2.1 The early years of digital storytelling (1993-2000).....	5
2.2 The spread of digital storytelling.....	7
2.3 Patient Voices: the beginning.....	7
2.4 Developing our practice and our method (2004-2009)	11
2.4.1 Discovering CDS/StoryCenter	11
2.4.2 Serving two masters	12
2.4.3 The first ‘open’ workshops – and some lessons learned	12
2.4.4 Interest grows and our practice develops	14
2.5 Digital storytelling in healthcare comes of age (2010-present).....	15
2.6 Chapter summary.....	17
References	18
Chapter 3: Theoretical foundations for the work of Patient Voices	21
3.1 Introduction	21
3.2 Reflection	21
3.3 Humanistic, holistic, emancipatory and transformational education.....	23
3.4 Healthcare quality improvement and the patient experience	24
3.5 Stories, narrative and the humanities in healthcare	25
3.6 The healing power of stories	27
3.7 Compassion and mindfulness.....	28
3.8 Epistemic injustice.....	29
3.9 The politics of listening and participatory media practice.....	30
3.10 Summary	31

References.....	31
Chapter 4: Introduction to the publications and the narrative	35
4.1 Introduction.....	35
4.2 List of publications and their context in this thesis	35
4.2.1 Adapting digital storytelling for use in healthcare: history, ethics and distribution	35
4.2.2 Digital storytelling in healthcare education	35
4.2.2 Digital storytelling with patients and people.....	35
4.3 The Journey Begins.....	36
4.4 First do no harm: developing an ethical process of consent and release for digital storytelling in healthcare.....	36
4.5 Patient Voices: the website www.patientvoices.org.uk	37
4.6 Tell me a story: a conceptual exploration of storytelling in healthcare	37
4.7 Challenging the shock of reality through digital storytelling	37
4.8 Physician know thyself: digital storytelling with medical students.....	38
4.9 Our stories ourselves: exploring identities, sharing experiences and building relationships through Patient Voices	39
4.10 Dangling conversations: reflections on the process of creating digital stories during a workshop with people with early stage dementia	40
4.11 Digital storytelling with users and survivors of the UK mental health system	40
4.12 Summary	41
References.....	42
Chapter 5: Adapting digital storytelling for use in healthcare: history, ethics and distribution.....	43
5.1 Introduction.....	43
5.2 The journey begins	43
5.3 Ethical issues in relation to digital storytelling in healthcare.....	45
5.4 The Patient Voices website: www.patientvoices.org.uk	46
5.4.1 Facts and figures.....	46
5.4.2 Who uses the stories and how do they use them?	50
5.5 Summary	50
References.....	51
Chapter 6: Digital storytelling in healthcare education	53
6.1 Introduction.....	53
6.2 Tell me a story: a conceptual exploration of digital storytelling in healthcare	54

6.3 Challenging the shock of reality through digital storytelling	55
6.4 Physician, know thyself: using digital storytelling to promote reflection in medical education	56
6.5 Summary	57
References	57
Chapter 7: Digital storytelling with patients and people	59
7.1 Introduction	59
7.2 Our stories ourselves: exploring identities, sharing experiences and building relationships.....	61
7.3 Dangling conversations: reflections on the process of creating digital stories during a workshop with people with early stage dementia	62
7.4 Digital storytelling with users and survivors of the UK mental health system.....	64
7.4 Summary	65
References	65
Chapter 8: Summary and conclusions	67
8.1 Overview	67
8.2 Contribution to new knowledge.....	68
8.3 Themes of the thesis	68
8.3.1 Using stories to understand the patient experience	69
8.3.2 Using storytelling to deepen reflective practice	69
8.3.3 A solid ethical foundation.....	70
8.3.4 Development and adaptation of digital storytelling methods.....	70
8.3.5 Addressing epistemic injustice	70
8.4 Limitations of the thesis	70
8.5 Future research	71
References	72
Appendix 1: List of clients and intended use of the stories	75
Appendix 2: Contribution to publications	84
Appendix 3: Contracts for publications in press	92

Chapter 1: Introduction

'These stories shouldn't be studied for the facts; but listened to for other melodies. Don't read history.... Listen to it sing.' (Hitt, 1994)

1.1 Background

Digital storytelling is all around us. The term is used to describe almost anything that is conveyed digitally which is, in the second decade of the 21st century, almost everything. Facebook posts, Twitter feeds, blogs, vlogs, podcasts, WhatsApp messages, Facetime calls, Snapchat, Instagram, short films, longer films, talking heads videos, video diaries and so on, as far as we can think of the ways in which people communicate the events in their lives, their hopes and aspirations, their joys and their sorrows.

It is important to note, from the outset, that this thesis is not intended to present the outcomes of research; rather it is a consideration of how the Patient Voices approach has contributed to the evolution of an emergent genre.

What was originally conceived as an emancipatory and democratising process of teaching ordinary people to use digital tools to share their life stories through the creation of their own short videos has, as a result of the rapid advance in digital technologies, become a ubiquitous term, with a wide range of definitions and an equally wide spread of influence both geographically and across the range of human experience.

The first digital storytelling workshop was held in 1993 (Lambert, 2002). The model of a carefully facilitated workshop for a small number of people combining elements of creative writing, reflection, careful listening, photography, community theatre and small group work has become known as the classical model of digital storytelling. Classical digital stories are short (two or three minute) videos that weave together a recorded voiceover, still images and/or short video clips and sometimes music or other sound effects into a rich tapestry of experience and reflection, characterised by the authentic voice of the storyteller and a degree of emotional openness that encourages viewers to connect with the storyteller and his or her experiences.

Some ten years after that first digital storytelling workshop, the Patient Voices Programme was founded in 2003 by Tony Sumner and myself, both directors of Pilgrim Projects, a small education consultancy specialising in healthcare quality improvement.

Initially developed as an educational resource to provide a balance for the prevalence of statistics and the kind of evidence-based healthcare that was based on the evidence of randomised control trials, Patient Voices set out to remind all those designing and delivering care of the importance of humanity and compassion by encouraging them to reflect on these short stories created by the people who receive and those who deliver healthcare – about their experiences of care – and sometimes the lack of it – and the impact of those experiences on their lives.

Since 2003, more than 1000 digital stories have been created during the course of well over 100 workshops; a website (www.patientvoices.org.uk) has been developed to serve as a valuable archive for the stories; papers have been published, presentations have been given, books have been written, awards have been won and we – and the Patient Voices Programme – have achieved world-wide recognition as the leading authorities on digital storytelling in healthcare.

As the first digital storytelling project in the world to focus exclusively on healthcare (as opposed to health promotion or public health), the Patient Voices Programme has laid the foundations and established best practice for other digital storytelling projects in both related and disparate areas. Our work in relation to ethical procedures and processes, our emphasis on the value of reflection and the thoughtful use of technology to convey important personal stories have influenced not only the stories that are produced as part of the Patient Voices Programme, but also the development of other digital storytelling projects and the creation of other digital stories around the world. As a result of the work of the Patient Voices Programme, digital storytelling is now viewed as a legitimate approach to communicating the experiences of patients, carers and healthcare staff, affecting clinical, as well as political and strategic, aspects of healthcare.

1.2 Aims of the thesis

This thesis sets out to document the development of digital storytelling in healthcare and to examine, in particular, the contribution that I have made, via the Patient Voices Programme, to the wider emergent genre of digital storytelling.

Eight peer-reviewed publications and one website will be considered and the thesis will explain how each of these has contributed to the body of knowledge in the growing, but still new, field of digital storytelling.

The publications span a range of issues that have emerged as the practice of digital storytelling has developed, such as ethical considerations, the therapeutic aspects of digital storytelling and the use of stories and storytelling as an educational tool, as well as highlighting different approaches to, and outcomes from, working with different groups, while the website presents the work of the Patient Voices Programme to the world.

1.3 Structure of the thesis

Chapter 1 has provided an introduction to the topic of digital storytelling in healthcare and offers an overview of the thesis.

Chapter 2 will provide an introduction to digital storytelling in healthcare, including the historical background.

Chapter 3 will discuss some of the theoretical constructs underpinning the thesis.

Chapter 4 will introduce the publications and the narrative.

Chapter 5 will consider the historical and ethical foundations for digital storytelling in healthcare and will look at the model of distribution.

Chapter 6 will focus on the use of digital storytelling and digital stories in healthcare education.

Chapter 7 will focus on working with patients and people.

Chapter 8 will provide a summary and draw some conclusions.

1.4 List of publications to be included in the thesis

The following table lists the publications that are included and the chapters to which each relates.

<i>Title</i>	<i>Authors</i>	<i>Publication details</i>	<i>Chapter</i>
The journey begins	Pip Hardy and Tony Sumner	The first chapter of <i>Cultivating Compassion: how digital storytelling is transforming healthcare</i> edited by Pip Hardy and Tony Sumner and published by Kingsham Press. 2014	Chapter 5
First do no harm: developing an ethical process of consent and release for digital storytelling in healthcare	Pip Hardy	Published in <i>Seminar.net</i> in 2015	Chapter 5
The Patient Voices Website	Tony Sumner and Pip Hardy	The official website of the Patient Voices Programme www.patientvoices.org.uk	Chapter 5
Tell me a story – a conceptual exploration of storytelling in healthcare	Carol Haigh and Pip Hardy	Published in <i>Nurse Education Today</i> 2010	Chapter 6
Challenging the shock of reality through digital storytelling	Gemma Stacey and Pip Hardy	Published in <i>Nurse Education in Practice</i> 2010	Chapter 6
Physician know thyself: using digital storytelling to promote reflection in medical education	Pip Hardy	Chapter included in <i>Digital Storytelling in Higher Education: International Perspectives</i> edited by Yngve Nordkvelle, Pip Hardy, Grete Jamissen and Heather Pleasants due to be published by Palgrave Macmillan in 2017	Chapter 6
Our stories, ourselves: exploring identities, sharing experiences and building relationships through Patient Voices	Pip Hardy and Tony Sumner	Chapter included in <i>Community-Based Multi-Literacies and Digital Media Projects: Questioning Assumptions and Exploring Realities</i> edited by Heather Pleasants and Dana Salter, published by Peter Laing in 2014	Chapter 7
Dangling conversations: reflections on the process of creating digital stories during a workshop with people with early stage dementia	Rosie Stenhouse, Jo Tait, Pip Hardy and Tony Sumner	Published in <i>Journal of Psychiatric and Mental Health Nursing</i> 2012	Chapter 7
Digital storytelling with users and survivors of the UK mental health system	Pip Hardy and Tony Sumner	Chapter included in <i>Story, Form and Content in Digital Storytelling: Telling Tales</i> edited by Mark Dunford and Tricia Jenkins, due to be published by Palgrave Macmillan in 2017	Chapter 7

References

Hitt, J. 1994. *Off the Road: A Modern-Day Walk Down the Pilgrim's Route into Spain*, New York: Simon and Schuster

Lambert, J. 2002. *Digital storytelling : capturing lives, creating community*, Berkeley, CA: Digital Diner Press.

Chapter 2: A history of digital storytelling in healthcare

'I believe the notion of story, transformative reflection, and the capacities of computing machine being forged together into some sort of new life management process is catching on with people.' Joe Lambert

This thesis sets out to document the growth of digital storytelling in healthcare and to examine, in particular, the contribution that I have made, via the Patient Voices Programme, to the wider emergent genre of digital storytelling.

2.1 The early years of digital storytelling (1993-2000)

Imagine a warm spring day in Los Angeles. It is February of 1993. Digital storytelling – the term and the practice – was still a twinkle in the eyes of a few visionary, West Coast film and theatre types.

The late Dana Atchley III had been performing a multi-media piece called *Next Exit* in San Francisco. The show consisted of Dana sitting by a virtual campfire projected onto the stage, and telling stories about his life by means of a series of videos that were also projected onto a screen at the back of the stage. The Silicon Valley technology boom was well underway and there was what Joe Lambert describes as a 'thunderous explosion of activity' as 'the potential of desktop computing reached the frontier of multimedia, still and moving image, text and sound' (Lambert, 2002).

Recent developments in technology had enabled Dana to bring his videos to the computer (remember this was ground-breaking in the early 1990s) and he was invited to perform his show at the American Film Institute's (AFI) last National Video Festival. The new technologies that enabled Dana to tell the stories of his childhood and youth, college years and early professional career perfectly complemented his performance style that was later described as 'direct and informal, conversational, populist, transparent and emotionally direct' (Lambert, 2002). The approach reduced the distance between him as a performer and his audience and held tremendous appeal for anyone who likes to hear a good story told well.

Meanwhile, a digital media lab had recently been developed as part of the AFI's work, utilising cutting-edge hardware and software that would make it possible for ordinary people to create their own movies. As a means of engaging people with the tools, Dana has

been asked to lead a workshop. Naturally, he invited his friend and collaborator, Joe Lambert, to come along, as much participant as co-lead. On a Friday evening, Joe and Dana met with seven storytellers. Joe later recalls:

'Dana had been a "studio" educator for years in his early career, and had a classic sort of get them started, show them a few things, and then help-as-you-go approach, not much method or pedagogy, but folks took to the process on the computers pretty well. Obviously computers of that era were a small pain in the ass to do anything.

We worked from 9-5 on Saturday and Sunday and I then left for San Francisco. Dana stayed in LA for the Tuesday showing. One of the stories that was shown at the screening was Monte Hallis' Tanya.' Lambert: personal communication 8th June 2016

The story Joe refers to, *Tanya*, was to become an inspiration for generations of future storytellers, setting the scene for hundreds of digital storytelling workshops, highlighting the clarity, precision, succinctness, honesty and simplicity, imbued with personal connection, that has come to characterise the best digital stories. Tanya can be seen here: <https://www.youtube.com/watch?v=D0zA9q7qJZc>

I doubt if any of the people involved could have imagined the impact of that first workshop on what was to grow into a genre in its own right with a significant impact in education, community development, oral history, film and media practices, the visual arts, public health and health promotion, marketing and advertising, conflict resolution, gender-based and domestic violence – to list but a few of the spheres in which digital storytelling has had an influence.

Two further workshops were held at the AFI and Joe Lambert found himself captivated, intrigued and 'inexplicably moved' by the process of transforming story into film and yet unable to define or characterise the workshop process. At once like and unlike lots of things, he recalls:

'The sense of transformation of the material, and of the accomplishment, went well beyond the familiar forms of creative activity I could reference. And even as the tools themselves frustrated me, I knew that this activity had a special power that could be shaped into a formal creative practice.'
(Lambert, 2002)

Within a year of the first AFI workshop, the San Francisco Digital Media Center had been set up and was offering digital storytelling classes using a number of different software programmes and it was not long before hundreds, and then thousands, of people had engaged in the compelling mix of storytelling, creative writing, digital photography and video editing that many storytellers have described as transformative. The name evolved to become The Center for Digital Storytelling and changed once again, in 2015, to Story Center (www.storycenter.org) to reflect the redundancy of the 'digital' part of the name in a world where everything is digital and to reflect the organisation's focus on the centrality of story and storywork over technology.

The early history of digital storytelling is more fully described in Joe Lambert's book, *Digital Storytelling: Capturing Lives, Creating Community* (Lambert, 2002), but I hope this brief summary helps to set the scene for what was to come.

2.2 The spread of digital storytelling

It didn't take long for the good news to spread far and wide. In 2001, The Center for Digital Storytelling (CDS) was approached to train a group of staff from BBC Wales and Cardiff University for a new project designed to bring the stories of the inhabitants of Wales to the nation's television screens. *Capture Wales*, headed up by photographer Daniel Meadows, ran regular (monthly) workshops around Wales until 2008, teaching members of the public how to use media production tools to share their unique personal experiences. *Capture Wales* workshops lasted for five days and had a production team of five or six people to ensure that the digital stories would be of sufficiently high quality to feature on public television. 600 stories were collected from people from around Wales and from a wide range of backgrounds; the stories can be seen here:

<http://www.bbc.co.uk/wales/arts/yourvideo/queries/capturewales.shtml>

While small digital storytelling projects were springing up around the UK (mostly offshoots of *Capture Wales*), CDS was forming alliances with, among other organisations, Australia's Museum of the Moving Image, the Queensland Institute of Technology and Brazil's Museum of the Person; the power of digital storytelling began to spread across the globe.

2.3 Patient Voices: the beginning

Just ten years after that first digital storytelling workshop in Los Angeles, in 2003, Pilgrim Projects (the education consultancy I had formed with my partner, Tony Sumner) was

working with the UK National Health Service Clinical Governance Support Team on a large-scale research and education programme with Board teams of primary care trusts. As the data came in, it became clear that Board teams were very uncertain about their understanding of the patient experience – one of the parameters that was being measured.

Around the same time, Pilgrim Projects had been commissioned by the Royal College of Nursing and the UK Health Education Partnership to develop two e-learning modules about clinical governance. As the principal writer, I had been charged with ensuring that the modules were not only interesting and engaging, accurate and up-to-date but also were creative, innovative and, above all, included ‘the voice of the patient’. Research conducted as part of the development of these two modules revealed pockets of excellence in healthcare in the UK and elsewhere in the world, but our experiences and those of friends and family did not always measure up to the high standards that I saw elsewhere. Armed with the evidence of our own experience and inspired by the evidence of best practice that I was discovering, I set out to explore ways of embedding the patient voice right at the very core of the resources. The question was: how best to do this?

To step back a few years.... I had been working in non-traditional adult education since the mid-1980s, teaching communication and liberal studies to hairdressers, welders and fabricators, shop assistants and administrative workers at the local further education college, as well as running evening classes in women’s studies and women’s literature. After a few years, I moved on to work with homeless and unemployed people at Actionline, a YMCA-funded project, before finding a job at the National Extension College (NEC) – the pilot project for what was to become the UK’s Open University (de Salvo, 2001) . Developing open and distance learning materials came easily to me; placing the learner at the centre of the learning experience, ensuring that the experience was active, engaging, accessible, motivating, clear, appropriate, relevant and, importantly, enjoyable seemed obvious to me and had underpinned my face-to-face teaching and became even more important in teaching at a distance and was an important way of promoting social justice and emancipation through education.

The use of stories (both real and made-up) came to characterise my work and were used to engage learners, illustrate points, provide examples, prompt reflection, stimulate action and assess learning. In some of these learning programmes, especially those designed to teach ‘soft’ skills or new behaviours, such as assertiveness and confidence for women returning to work and higher education (Hardy and Clarke, 1990) (Hardy and Snedegar,

1993); listening skills for managers; counselling skills for teachers and social workers (Giffin and Hardy, 1994); managing stress, etc., stories were also used as an innovative form of assessment (Hardy, 1991): changes in learners' knowledge, skills and behaviours were evaluated by short, reflective stories offering concrete examples of what learners had accomplished as a result of new learning.

By the time Pilgrim Projects was established in 1999, I had been putting stories to good use in a number of open learning and work based learning programmes – but these had, for the most part, been print-based and I wanted to make the best use of the opportunities afforded by e-learning technologies.

It was in the autumn of 2003 when I first saw a digital story – a very short piece about a mother's love for her daughter, created as part of a community history project in Milton Keynes (Judd, 2002). In less than two minutes, I had been moved to tears. I realised that using this format for patient and carer stories would breathe life into the clinical governance e-learning modules, serving to illustrate both good and poor practice, prompt reflection, stimulate discussion and debate and, most importantly, touch hearts as well as minds.

Funding was made available from the Clinical Governance Support Team, the first two storytellers were found and Patient Voices was born. I worked closely with our friend and colleague, Brendan Routledge, who had shown us that first story and who had learned about digital storytelling via Roger Kitchen who had, himself, been influenced by the *Capture Wales* project. I had not yet heard of the Center for Digital Storytelling.

Initially our process involved spending time with storytellers, getting to know them and putting them at their ease before embarking on something between a semi-structured interview and a conversation. The intention was to create stories that would bring to life the values of clinical governance, that is: equity, justice, respect and trust (Stanton, 2004). Story prompts were along the lines of 'Tell me a story about trust/equity/justice. etc.' When the storyteller flagged, I might ask a question or seek more detail. Brendan videoed this interaction and did the follow-up production work, editing the recording down to two or three minutes, intercutting the video of the interview with photos supplied by the storytellers and adding some music. When this work was complete, there was another meeting with the storytellers so that they could see the resulting digital story and either suggest amendments or approve the movie. Our first two storytellers helped us create a

robust and ethically sound consent and release form and told us how helpful it was to share their stories with us (Hardy, 2015).

Priding ourselves on the catchy titles we would think up for learning programmes, we called the new project 'Patient Voices', playing on the two meanings of the word 'patient', always knowing we wanted to hear stories of patients, carers *and* the people who provide healthcare, so many of whom had been waiting so patiently to be heard. From a business perspective, we thought that the use of digital stories in our e-learning materials would give us the edge on competitors. From a personal point of view, my aspiration was to transform healthcare by bringing these deeply affecting stories of personal experience to the attention of those who design and deliver healthcare. I could not see how they could fail to be touched by the honesty and directness of the stories. But even with that lofty aspiration, I did not dare to assume that Patient Voices would soon become our main endeavour and, indeed, my life's work.

The stories were duly embedded in the clinical governance e-learning modules and also shown to Board teams where they were there to serve as a way of focusing the collective mind of the Board on the experiences and feelings of the people (Stanton, 2014). Paul Stanton, head of board development, later told us that he quickly became accustomed to 'the pin-drop effect' – the awed (and sometimes stunned) silence in the room in response to a digital story, but which led to creative and productive discussion around the issues raised in the story.

Within a year of recording the first Patient Voices stories, there was a DVD containing 26 stories from patients, carers, a volunteer working with a Stroke charity, a medical doctor and the parents of a young man who had been an organ donor. We had won our first awards and, in response to requests for evidence of impact, I had enrolled at the University of Ulster on an MSc in Lifelong Learning, delivered via e-learning.

More of the history of the Patient Voices Programme is contained in the first three chapters of *Cultivating compassion: how digital storytelling is transforming healthcare* (Hardy and Sumner, 2014) so, having set the scene, I will briefly summarise some of the key aspects of the development of digital storytelling in healthcare which, as far as it is possible to determine, is the development of the Patient Voices Programme.

2.4 Developing our practice and our method (2004-2009)

We were fortunate in our connections and it was not long before we were introduced to Karen Taylor, then Director of the Value for Money Audit at the National Audit Office. She spotted the potential of digital stories to support her report on stroke care in England by giving life to the statistics and commissioned Pilgrim Projects to create a DVD of stories of people affected by stroke to accompany the report that she would later present to the Public Accounts Committee. Working with people suffering from aphasia (difficulties with speaking, reading and writing) resulting from a stroke was not easy and we didn't yet know about story circles. We worked with a small group of storytellers, often using photographs as prompts for parts of the story, recording and re-recording to get the best possible voiceover and then editing the pauses and stutters and stammers as much to honour the storytellers as to ensure that viewers' experience of the story would not be compromised by the inevitable lengthy hesitations.

This early use of the stories in support of statistics helped to assure us that this work and these stories could make a difference to people's lives. The 'Reconnecting with Life' stories can be seen here: www.patientvoices.org.uk/naoconn.htm

2.4.1 Discovering CDS/StoryCenter

Early in 2006, I went to California to participate in one of the Center for Digital Storytelling's digital storytelling workshops and returned a few months later for their week-long facilitator training. Having experienced the benefits of the story circle approach and gained more confidence in the skills of group facilitation, as well as a number of the technical skills, I was determined to change our own approach and method to resemble more closely the CDS model. The CDS approach, grounded as it was in community arts, grass-roots social activism and the Freirian concept of *consciencization* (Freire, 1970) chimed with our vision of bringing social justice to healthcare and transforming the health service from the ground up by offering patients and others 'convivial tools' (Illich, 1973) with which they could gain insight into their lives, make meaning of their experiences, and share those experiences widely.

The first opportunity to practise with a story circle was with some staff and patients working with the NHS Heart Improvement Programme – they had seen the value of digital stories to illuminate the impact of heart disease on people's lives. That first story circle

went well and every Patient Voices workshop since then has incorporated this important element of the classical digital storytelling process.

Meanwhile, colleagues at the Royal College of Nursing (RCN) were keen to explore the potential of digital storytelling as part of their quality improvement programme. A project intended to improve continence care in care homes resulted in intimate stories that revealed the often-heart-breaking impact of incontinence on the lives of people suffering from dementia, Parkinsons and Rheumatoid Arthritis – and those caring for them. The stories can be seen here: www.patientvoices.org.uk/rcngip.htm

2.4.2 Serving two masters

We were beginning to learn about one of the tensions inherent in Patient Voices' work: that of pleasing two masters. Clearly, it was important to provide our clients (those people or organisations who commissioned us to create digital stories with their staff or service users) with a useful product (the stories), but we were also committed to helping storytellers tell the most important story they needed to tell (the process).

Occasionally, misunderstandings about the digital stories and the most appropriate ways of using them emerged. For example:, the RCN initially thought they wanted training videos, something that would 'meet our learning outcomes'. I explained that this was not what digital stories were about. After a bit of to-ing and fro-ing, they agreed to trust our process. Once they saw the stories, they realised that, after all, their learning outcomes were not based on what really mattered to patients and their carers. Their response was to adjust the curriculum, revise their learning outcomes and build their educational resource around the stories rather than trying to make the stories fit pre-existing learning outcomes (Hardy, 2007). This was a major step forward in understanding the capacity of digital stories to be a valuable resource in their own right, rather than used as training videos. It also confirmed our hypothesis that allegiance to storytellers would also provide clients with what they needed in terms of stories. Nevertheless, we adapted our briefing process to ensure that clients understood this potential tension and that the best way of ensuring customer satisfaction was for us to maintain both humility and curiosity and to learn as much as possible about their project and its aims.

2.4.3 The first 'open' workshops – and some lessons learned

In June of 2007, we conducted our first 'open' workshop, following up on interest in a digital storytelling masterclass jointly organised with CDS here in the UK earlier that year.

Considerable time was spent adapting the CDS materials to our own context, creating a teaching story (based on a prompt given by Joe Lambert at a digital storytelling retreat in 2006) and writing our own 'cookbooks' to accompany the CDS Cookbook, using our own example photos and videos for teaching. Nine people attended that first workshop, held over an intensive weekend. Somewhat to our amazement, everyone finished a story and we were able to celebrate this success with a premier of stories on the Sunday evening.

Several more of these weekend workshops followed, attended by people from university schools of healthcare and other healthcare organisations who were interested in the possibility of using digital stories or digital storytelling in their institutions. We learned a great deal about facilitation and technology, about consent and release, and generally about managing the process. One of the most important lessons was in relation to technology. For these early workshops, participants brought their own laptops, and so we had a mix of Apple and PC laptops. Some people came with very old laptops with insufficient space or processing power for the demands of video editing; others came without administrator passwords and precious time was lost trying to resolve these problems, as well as installing trial versions of the software necessary to create the digital stories (in our case, Adobe Premier Pro). It was not long before we realised that we would have to invest in our own suite of laptops to ensure the smooth running of the workshop, provide the best experience to participants and make our lives much easier.

Another important lesson learned from those early workshops was the importance of gathering everyone at the workshop venue the night before the workshop was to begin. Late arrivals, combined with the various technical problems meant that our precious two days was often reduced to little more than 1 ½ days – too little time to create a reflective digital story. So we began inviting people to arrive on Friday evening so that they could meet the other participants and share a meal together. The Friday evening supper was to become another key feature of our open workshops, allowing us to start work in earnest first thing on a Saturday morning with a clear two days ahead.

A month after our first open workshop, in July of 2007, I graduated with a distinction for my MSc dissertation investigating the impact of digital stories in healthcare education and quality improvement work (Hardy, 2007). The dissertation can be accessed here:

www.pilgrimprojects.co.uk/papers/phardymsc.pdf

2.4.4 Interest grows and our practice develops

Meanwhile, interest in Patient Voices was growing. In the wider world of the NHS, there was increasing recognition of the need to listen to patient stories in order to gain a better understanding of the care they were receiving. Participants in the first few open workshops had taken their new learning back to the NHS in Scotland, where a digital storytelling project was set up to collect the stories of people affected by COPD and, later, stroke. Projects were undertaken with the Universities of Leeds, Huddersfield and Sheffield Hallam and work continued with the Royal College of Nursing. We continued to hone our skills and strengthen our collaboration with CDS; this included joint presentations at international conferences and co-facilitation at several workshops.

One of these presentations resulted in a chance meeting that revealed yet another use for digital storytelling. The University of Saskatoon had delivered a Live Well™ programme to a group of First Nation Peoples affected by diabetes. Struggling to find an effective method of evaluating the effectiveness of the programme in terms of the impact on people's lives, a decision was made to include digital stories created by the participants to illuminate the more numbers-based elements of the formal evaluation. We had been prepared to work with people with little education, living in poverty with few resources and with a heavy burden of chronic disease, including mental illness, and we were not surprised. By coincidence, we found ourselves working in Sheffield (UK) just a week or so later and were struck by the similarities in the circumstances of several of the storytellers, all of whom were affected by one or more chronic conditions, including mental illness. I began to realise that people are more similar than they are different and poverty results in suffering, wherever it is found.

The stories from Saskatoon can be seen here: www.patientvoices.org.uk/sask.htm

The stories from Sheffield can be seen here: www.patientvoices.org.uk/shu.htm

Conference presentations became a more regular part of my work, not only as a result of accepted abstracts but also from some invited presentations. In addition to honing facilitation skills, I was improving presentation skills, refining PowerPoint presentations, beginning to collaborate with others in presentations and symposia and consolidating Patient Voices' reputation as leaders in the field.

We ran our first facilitator training workshop in the summer of 2008 with the help of Joe Lambert, who came over from California to oversee the training of the new facilitators who, we hoped, would continue to support the work of Patient Voices within their institutions.

The collection of stories was growing and the variety of uses for them was expanding. Stories told by patients and carers were being used in schools of medicine and healthcare and in NHS and other healthcare organisations around the world to remind students of the humanity of the people they would be caring for. Staff and students were also creating stories about their experiences of working in healthcare sometimes as a means of developing a more reflective practice (Anderson, 2011) (Anderson and Kinnair, 2014) and sometimes to serve as guidance for preceptors and other students as to what they might expect in the wider world of clinical practice (Stacey and Hardy, 2011).

2.5 Digital storytelling in healthcare comes of age (2010-present)

2010 was a momentous year. Our focus on quality and safety included workshops in the US and Australia as well as closer to home in Leeds and Sheffield. Increasingly, we were hearing stories about mental health issues and also realising the potential benefits of the digital storytelling process for people with mental health. Our experience was borne out when the commissioner of a workshop with carers of people affected by mental illness decided to focus his MSc on the potential therapeutic benefits of the process; it was no surprise to us when he found that digital storytelling did indeed have a number of benefits for storytellers, as well as producing stories that could educate others (Shea, 2010).

2010 was the year we were awarded the prestigious *British Medical Journal* (BMJ) award for Excellence in Healthcare Education; we were also runners up for the BMJ Health Communicator of the Year award and the Medical Journalists' Association Health Champion of the Year. In our statement for the latter award, we noted:

'When a flight nurse from Ohio, a patient with enduring mental illness from Australia and a man with rheumatoid arthritis from Leeds all tell us that a digital storytelling workshop has changed their lives, we are reminded that, "that which unites us is greater than that which divides us".'

By 2010 we had a strong group of allies who were interested in the potential of digital stories to bring greater humanity to healthcare and several mini-conferences were held to share ideas and explore opportunities for collaboration. Patient Voices had featured in at

least two PhDs (Moss, 2012; Wang, 2012). A quarterly newsletter was distributed to storytellers, commissioners of workshops and other interested people. We had settled into a regular way of working and had several trustworthy assistant facilitators who were happy to help out during workshops.

Then came recession, austerity and cut-backs in public sector spending, including the NHS.

One of the bright spots during that dark time was the beginning of our work with Manchester Mental Health and Care NHS Trust. The first workshop, held in November of 2011, produced five stories which were, with some trepidation, shown to the Board. Nearly five years, 11 workshops and 70-odd stories later, the stories have had a significant impact on the Trust: care has improved, complaints and clinical negligence claims have reduced, patients and carers are more involved in the Trust, every Board meeting begins with a story and staff recruitment interviews always include a story (Haigh et al., 2013) (Sumner, 2013). The impact of these stories has inspired others to believe that stories created by their own particular service users might also have such a wide impact on their service delivery while, for us, the benefits for the storytellers are every bit as important as the potential for improvements in service delivery.

Working with mental health service users is as challenging as it is rewarding and has led us to embed clinical supervision firmly in our practice to ensure our own wellbeing so that we can continue to work with others in way that are safe and contained for all concerned (Hardy and Sumner, In press).

Meanwhile, in the wider world of digital storytelling, we at Patient Voices were becoming established as the leading world experts in digital storytelling in healthcare. Keynote talks at several international digital storytelling conferences in Portugal, Norway, Turkey and Greece gave us the opportunity to share our growing knowledge and wisdom about working in the realms of illness, accident, disease, despair and suffering as well as those of courage, determination and resilience. As a result of the *BMJ* Award, I was invited to Hong Kong to deliver the keynote at the 2011 Quality Conference; other invitations took us to Norway, once again in 2012, to speak about our experiences of creating digital stories with people with dementia (Stenhouse et al., 2012) and closer to home, to speak at the London School of Hygiene and Tropical Medicine during Global Mental Health week in 2013. Our work with medical students at Kings College in London confirmed our understanding (and built upon the work of others such as John Sandars (Sandars et al., 2008) (Sandars, 2009)) that digital storytelling is an effective way to teach the skills of reflection; the stories that

were made restored our faith in a healthcare system that might be populated by clinicians who see their patients more as people than as collections of symptoms (Hardy, In press).

In 2014, we edited the first book to be published about digital storytelling in healthcare (Hardy and Sumner, 2014): a collection of chapters written by colleagues who had commissioned workshops and a conference was held to celebrate the launch of the book; it was attended by healthcare colleagues from the UK and digital storytelling colleagues from Europe and the US. Keynote talks were delivered by Joe Lambert, Neil Churchill (Director of Patient Experience for NHS England) and Helen Bevan, Chief of transformation for NHS England.

The following year was a bumper year for conferences with no less than 14 presentations in England, Scotland and Wales as well as Missouri and Georgia in the USA; most of these were invited keynote presentations on topics ranging from interprofessional education through compassion and decision making to DS as a visual method and stories as a means of bringing about transformational change. All these presentations can be seen here: www.patientvoices.org.uk/present.htm

To bring the story of digital storytelling in healthcare up to date, 2016 has seen the confirmation of something we have long known: the importance of the staff experience and the value of their stories. The *DNA of Care* project, commissioned by NHS England, emerged from the realisation that staff experiences and patient experiences are inextricably linked (Maben et al., 2012). The project consisted of five Patient Voices workshops for NHS staff across the interprofessional spectrum. Not only are the stories that were created being used to educate others, but the experience of creating digital stories was felt to be therapeutic – even cathartic, with storytellers commenting that the process provided a valuable and rare opportunity to reflect, akin to good clinical supervision. Indeed, one consultant even commented, several months after the workshop, that she is a better doctor since creating her story. One London teaching hospital plans to show a story at every monthly staff meeting as a way of engaging staff with what really matters to them. The DNA of Care stories can be seen here: www.patientvoices.org.uk/dnaoc.htm

2.6 Chapter summary

This chapter has provided a chronological overview of the development of the Patient Voices Programme. The chapter began by setting the scene with a brief history of digital storytelling before going on to explain how the Patient Voices Programme began and has

since grown to be acknowledged as leading the world in digital storytelling in healthcare. The chapter has examined how the Patient Voices methodology developed and changed in response to the needs of different groups and considered the expanding range of uses for both the process of creating digital stories and the stories that result from that process.

References

- Anderson, E., Hardy, P., Kinnair, D., Sumner, T. and Thorpe, L. . 2011. They just don't get it: using digital storytelling to promote meaningful undergraduate reflection.
- Anderson, E. & Kinnair, D. 2014. Reflection – they just don't get it! Digital stories from junior doctors. *In: Hardy, P. & Sumner, T. (eds.) Cultivating compassion: how digital storytelling is transforming healthcare*. Chichester: Kingsham Press.
- de Salvo, A. 2001. *A brief history of the National Extension College*, Cambridge: National Extension College.
- Freire, P. 1970. *Pedagogy of the Oppressed*, New York: Bloomsbury.
- Giffin, S. & Hardy, P. 1994. *Counselling Skills Resource Bank*, Cambridge: National Extension College.
- Haigh, C., Cahoon, P. & Sumner, T. 2013. Working with dignity and respect: improving mental health services. *In: Hardy, P. & Sumner, T. (eds.) Cultivating compassion: how digital storytelling is transforming healthcare*. Kingsham Press.
- Hardy, P. 1991. *Return to the Office: LCCIB Profile Book*, Cambridge: National Extension College.
- Hardy, P. 2007. *An investigation into the application of the Patient Voices digital stories in healthcare education: quality of learning, policy impact and practice-based value*. MSc in Lifelong Learning MSc dissertation, University of Ulster.
- Hardy, P. 2015. First do no harm: developing an ethical process of consent and release for digital storytelling in healthcare. *Seminar.net: Media, Technology & Life-Long Learning*, 11.
- Hardy, P. In press. Physician, know thyself: using digital storytelling to promote reflection in medical education. *In: Nordkvelle, Y., Jamissen, G., Hardy, P. & Pleasants, H. M. (eds.) Digital Storytelling in Higher Education: International Perspectives*. London: Palgrave Macmillan.
- Hardy, P. & Clarke, F. 1990. *Return to Work: a Course for Women*, Cambridge: National Extension College Trust Limited.
- Hardy, P. & Snedegar, J. 1993. *Planning for Higher Education*, Cambridge: National Extension College.
- Hardy, P. & Sumner, T. 2014. *Cultivating compassion: how digital storytelling is transforming healthcare*, Chichester: Kingsham Press.
- Hardy, P. & Sumner, T. In press. Digital storytelling with users and survivors of the UK mental health system *In: Dunford, M. & Jenkins, T. (eds.) Story, Form and Content in Digital Storytelling: Telling Tales* London: Palgrave Macmillan.
- Illich, I. 1973. *Tools for conviviality*: Harper and Row.
- Judd, J. 2002. *Don't judge a book by its cover* [Online]. E2BN. Available: <http://clips.e2bn.org/view.php?id=110> [Accessed March 2014].
- Lambert, J. 2002. *Digital storytelling : capturing lives, creating community*, Berkeley, CA: Digital Diner Press.
- Maben, J., Peccei, R., Adams, M., Robert, G., A, R., Murrells, T. & Morrow, E. 2012. Patients' experiences of care and the influence of staff motivation, affect and wellbeing. Final Report. Southampton: National Institute for Health Research Service Delivery and Organisation Programme.

- Moss, M. A. 2012. *Critical story sharing as communicative action in organisational change*. PhD doctoral thesis, University of Waikato.
- Sandars, J. 2009. The use of reflection in medical education: AMEE Guide No. 44. *Medical Teacher*, 31, 685-695.
- Sandars, J., Murray, C. & Pellow, A. 2008. Twelve tips for using digital storytelling to promote reflective learning by medical students. *Medical Teacher*, 30, 774-777.
- Shea, M. 2010. *An exploration of personal experiences of taking part in a digital storytelling project*. MSc MSc dissertation, Sheffield Hallam.
- Stacey, G. & Hardy, P. 2011. Challenging the shock of reality through digital storytelling. *Nurse Educ Pract*, 11, 159-64.
- Stanton, P. 2004. *The Strategic Leadership of Clinical Governance in PCTs*: NHS Modernisation Agency.
- Stanton, P. 2014. Towards compassionate governance: the impact of Patient Voices on NHS Leadership. In: Hardy, P. & Sumner, T. (eds.) *Cultivating compassion: how digital storytelling is transforming healthcare*. Chichester: Kingsham Press.
- Stenhouse, R., Tait, J., Hardy, P. & Sumner, T. 2012. Dangling conversations: reflections on the process of creating digital stories during a workshop with people with early stage dementia. *Journal of Psychiatric and Mental Health Nursing*.
- Sumner, T. 2013. How we can recruit for compassion. *Health Service Journal*.
- Wang, X. 2012. *A genre theory perspective on digital storytelling*. Doctor of Philosophy in Education, Vanderbilt University.

Chapter 3: Theoretical foundations for the work of Patient Voices

‘Storytelling is the mode of description best suited to transformation in new situations of action.’ (Schön, 1988)

3.1 Introduction

Digital storytelling is a multidisciplinary activity, drawing on the theory and practice of a wide range of disciplines, from literature, drama, film, education and lifelong learning through creative writing, communication and photography, to counselling, group work, the humanities and beyond. Patient Voices’ focus on healthcare also draws on literature and policy relating to healthcare quality improvement and the patient experience.

This chapter discusses some of the epistemological and ontological foundations that have been most influential on the work of the Patient Voices Programme. In particular, I will consider the influence of the literature of:

- reflection
- transformational learning
- holistic, emancipatory and transformational education
- healthcare quality improvement and the patient experience
- stories, narrative and the humanities in healthcare
- compassion and mindfulness
- the healing power of stories
- epistemic injustice
- the politics of listening and participatory media practice.

3.2 Reflection

The Patient Voices Programme began with the intention of providing those engaged in healthcare design, delivery and education with an unusual opportunity to reflect on practice; one that differed from the reflective frameworks that were commonly in use at the time.

Previous work developing and consulting on open learning programmes for healthcare practitioners had built on the foundations of critical incident analysis (Flanagan, 1954), reflective models developed for use in education and healthcare (Tripp, 1993) (Johns and Graham, 1996) and, of course, the work of the famous educator, John Dewey who pointed out that 'We do not learn from experience, we learn from reflecting on experience' (Dewey, 1938).

The work of Jennifer Moon in highlighting the importance of reflective writing (Moon, 2004) , David Kolb's influential learning cycle (Kolb, 1983) as well as the work of David Boud and colleagues (Boud et al., 1985) had also informed my approach to developing reflective open learning programmes, such as the BSc in Professional Practice (Healthcare) published by Macmillan Open Learning in 1996 and the SESAME programme (Hardy, 2002). Indeed, as early as 1996, I had been exploring the potential of new technologies to influence and deepen reflection (Hardy and Redfern, 1997), utilizing email and discussion threads and electronic journaling to foster learning and reflection.

In the context of digital storytelling and reflection, the literature is scant but growing. Helen Barrett was one of the first people to see the potential of digital storytelling as a means of promoting learning and reflection in education and the use of digital stories in e-portfolios (Barrett, 2006); her findings were underpinned by the work of McDrury and Alterio which, in turn, builds on the foundation laid by Jennifer Moon in supporting the use of storytelling in higher education (McDrury and Alterio, 2003).

The use of digital storytelling with healthcare students in Norway has informed my thinking about 'the personal professional story' as well as the notion of 'poetic reflection' (Jamissen and Skou, 2010) as key parts of the process of shaping professional identity, while Thompson Long and Hall's longitudinal research with education students in Ireland has confirmed that digital storytelling has an important role to play in developing reflective skills in professionals (Thompson Long, 2014).

No consideration of reflection would be complete without mentioning the work of Donald Schön whose words are frequently quoted in presentations and writing about Patient Voices and support the use of digital storytelling as a powerful means of reflecting on action as well as reflecting in action (Schön, 1988) (Schön, 1987).

3.3 Humanistic, holistic, emancipatory and transformational education

Just as the concept of open learning was intended to make education accessible for people outside the traditional student population, and the concept of lifelong learning recognizes that valuable learning goes on throughout life and outside the classroom, so digital storytelling offers to anyone the possibility of creating a short video, including those without prior knowledge of the necessary tools for their creation. In this way, digital storytelling is founded on the revolutionary work of Paulo Freire and his contention that education, as a means of raising critical consciousness, was key to liberation for the world's poor and disadvantaged (Freire, 1973) (Freire, 2000).

Malcolm Knowles' contribution to adult education, encapsulated in his concept of 'andragogy', recognized that adults not only continue to learn throughout life, but that they do it in particular ways that rely strongly on motivation and the opportunity to work in groups (Smith, 2002). In this respect, he was deeply influenced by another great 20th century educator, Carl Rogers, whose recognition of the importance of groups and communities, and the need for 'core conditions' to be established in order to facilitate learning provides a cornerstone for the practice of digital storytelling, relying as it does on good facilitation to create a safe, communal space in which learning and change can happen (Smith, 2001, 2009). Another key figure in the world of humanistic and adult education in the second half of the 20th century was Parker Palmer, whose work on the spiritual aspects of learning and education had a particular resonance, helping me to make sense not only of my own journey but also of the experiences of the storytellers with whom we worked, many of whom commented on the 'almost spiritual' nature of the process:

'A knowledge born of compassion aims not at exploiting and manipulating creation, but at reconciling the world to itself. The mind motivated by compassion reaches out to know as the heart reaches out to love.... In such knowing we know and are known as members of one community and our knowing becomes a way of reweaving that community's bonds.'

(Palmer, 1983)

His eloquent articulation of the crucial links between the head and the heart echoed the immortal words of Gandhi, which encapsulate fundamental aspects of what the Patient Voices Programme is trying to accomplish and which, therefore, appear in almost every Patient Voices presentation: 'The culture of the mind must be subservient to the culture of the heart' (Gandhi, 1869-1948).

Barbara Carper's synthesis of the different kinds of nursing knowledge that are necessary for safe but also humane practice (Carper, 1978) gave credibility to my belief that digital storytelling could augment scientific ways of knowing with aesthetic, personal and moral ways of knowing.

My own attempts to make the connections between all these theories, together with a growing recognition of the importance of communities of practice (Wenger, 1999) and the potential of digital stories and digital storytelling to bring about transformation was expressed in the conclusion to my MSc dissertation (Hardy, 2007) where I was able to link learning, healing, knowing and the transformation that arises from reflecting on layers of meaning: 'Learning is a kind of healing; education a progression towards wholeness'.

3.4 Healthcare quality improvement and the patient experience

In 2001, the UK Department of Health stated its ambition to 'create a patient-centred NHS' (DH, 2000). The next few years saw the publication of a series of documents that reinforced the view that patients' experiences and views should be taken into account in the process of redesigning and modernising healthcare so that it truly placed patients at the heart of care. The Bristol Inquiry into the needless deaths of a number of children in the Bristol Royal Infirmary's heart unit led to the establishment of clinical governance as the NHS's main vehicle for ensuring quality and safety in care (Kennedy, 2001;DH, 2002) to be delivered by the Modernisation Agency's National Clinical Governance Support Team. Research undertaken by Paul Stanton to identify the degree to which NHS Trust Board teams understood the nature and implications of clinical governance was to have a significant influence on early Patient Voices work (Stanton, 2004), fueling our hypothesis that the use of stories were a means of promoting greater understanding of the *why* behind the *what* and the *how* of healthcare quality improvement. Early support for the use of patient stories in healthcare quality improvement came from Wilcock *et al* in their recommendation of the use of Discovery Interviews (Wilcock et al., 2003).

Meanwhile, work in the USA and elsewhere was also focusing on the need for healthcare reform, resulting in safer, higher quality care characterized by greater involvement of patients (IoM, 2001). The Clinical Microsystems Group at Dartmouth Medical School in the US was doing ground-breaking work highlighting the importance of following the patient journey and involving patients in decisions about their care (Nelson et al., 2002;Batalden et al., 2003).

Meanwhile, Ben Page at IPSOS Mori had conducted research revealing that, actually, patients cared more about being treated with dignity, humanity and respect than they did about mortality rates (Page, 2004); Muir Gray had written *The Resourceful Patient*, a helpful guide to the use of new technology as a means of empowering patients (Gray & Rutter, 2002) and Angela Coulter was spearheading the drive for greater patient involvement while questioning the appropriateness of the information that was available for them (Coulter et al., 1999). Her work at the Picker Institute was another early inspiration for the work of the Patient Voices Programme.

The government's ambition to involve patients more actively in their care was matched by the patient involvement movement and the recognition that patients do, indeed, have some expertise in their conditions, especially those affected by long-term chronic conditions. The Stanford Chronic Disease Management model (Lorig et al., 2001) became the Expert Patient Programme in the UK (DH, 2001) (Donaldson, 2003) and it was from there that the first two Patient Voices storytellers came.

3.5 Stories, narrative and the humanities in healthcare

One of the ways of acknowledging and learning from the experiences of patients was by listening to their stories; this represented something of a challenge to the more traditional and well-established methods of conducting research in healthcare.

Among the early heroes of the Patient Voices Programme was Trish Greenhalgh who, through a series of articles in the *British Medical Journal*, highlighted the value of patient stories in any attempt to understand and engage with patients (Greenhalgh and Hurwitz, 1998) (Greenhalgh and Hurwitz, 1999).

Around the same time, Brian Hurwitz and Rita Charon, among others, and others had pioneered 'narrative medicine', the use and appreciation of stories in many different forms to foreground the need for an understanding of humanity (Charon, 2001) (Hurwitz et al., 2004) and to provide a balance for 'evidence based healthcare' (Sackett, 1997), which relied mostly on the results of Randomised Control Trials. Charon's ongoing Programme of Narrative Medicine at Columbia University has continued to encourage and inspire our work at Patient Voices, while the publication in 2006 of *What seems to be the trouble? Stories in illness and healthcare* (Greenhalgh, 2006) also supported the value of stories in the scientific world of medicine.

A small but growing collection of books of stories told by patients was becoming more available and influential, including, for example Jean-Dominique Bauby's *The Diving Bell and the Butterfly* (Bauby, 1997) with its painful elucidation of locked-in syndrome, but also Susan Sontag's incomparable meditation on the language of illness (Sontag, 1990) which offers so much insight into how the language we use affects our understanding of illness. We at Patient Voices were particularly impressed by Anatole Broyard's book about his own cancer journey from which one of our favourite and most-often used quotations comes:

'To the typical physician, my illness is a routine incident in his rounds, while for me it's the crisis of my life. I would feel better if I had a doctor who at least perceived this incongruity... I just wish he would... give me his whole mind just once, be bonded with me for a brief space, survey my soul as well as my flesh, to get at my illness, for each man is ill in his own way.'

(Broyard, 1992)

In support of the use of stories to illuminate the human (as opposed to just the clinical) experience of patients, carers and the professionals who look after them, Christina Baldwin's *Storycatcher* (Baldwin, 2005) was an early source of inspiration, arguing for the centrality of stories in our lives as individuals, as members of families, groups, organisations, societies and cultures. She argues that sharing stories can contribute to greater understanding, empathy and compassion, goals which were very much in tune with those of the Patient Voices Programme in the quest for transformation and compassion. Edward Chamberlin also contributed to my understanding of the need for stories to make sense of our lives and our cultures, highlighting the ambiguous, and sometimes mysterious, nature of stories that allows space for wonder and wondering, particularly pertinent to the world of healthcare and the particular suffering that illness entails:

'Every story brings the imagination and reality together in moments of what we might call faith. Stories give us a way to wonder how totalitarian states arise, or why cancer cells behave the way they do, or what causes people to live the streets... and then come back again in a circle to the wonder of a son.. or a supernova.... Or DNA. Wonder and wondering are closely related, and stories teach us that we cannot choose between them. If we try, we end with the kind of amazement that is satisfied with the first explanation, or the kind of curiosity that is incapable of genuine surprise. Stories make the world more real, more rational, by bringing us closer to the irrational

mystery at its centre. Why did my friend get sick and die? Why is there so much suffering in the world? Whose land is this we live on? How much is enough?’ (Chamberlin, 2006)

In our work with both storytellers and viewers of stories, we encourage an awareness of the ambiguities, uncertainties and even mysteries inherent in the stories. It is our hope – and often our experience – that exposure to stories that ‘bring together the imagination and reality’ render storytellers and viewers more able to tolerate the ambiguities in their own lives and in the lives of others.

Before moving on, it is necessary to comment on our use of the word ‘story’ rather than ‘narrative’. We took, as an early *dictum* of Patient Voices, the words attributed to Pascal that ‘We tell stories to entertain and to teach’. We wanted viewers to engage with the stories; when we – or our children – want to be entertained, we are unlikely to say ‘Please tell me a narrative.’ Jeanette Winterson claims that ‘Stories are always true; it’s the facts that mislead.’ (Winterson, 2007) My own distinction is this:

‘Although some authors use the word ‘narrative’ as a synonym for ‘story’, narrative can be defined as predominantly factual whereas stories are reflective, creative and value laden, usually revealing something important about the human condition.’ (Haigh and Hardy, 2011)

3.6 The healing power of stories

‘To remember requires language, to heal requires story.’ (Baldwin, 2005)

Although the work of the Patient Voices Programme was, initially, to improve the quality of care for patients through the sharing of completed stories, it was not long before we recognized the healing power of the digital storytelling process. I have already mentioned the work of Anatole Broyard whose final book, as well as providing justification for more personal care from health professionals, also helped him to face his own impending death from cancer (Broyard, 1992).

James Pennebaker’s ground-breaking research into the therapeutic benefits of regular writing about emotional subjects (such as childhood trauma) have helped us understand why the digital storytelling process may be so helpful for so many people (Pennebaker, 1997) and inspired our colleague, Mark Shea, to undertake his masters research into the experiences of one cohort of Patient Voices digital storytellers. His research substantiated

Pennebaker's claim for the benefits of therapeutic writing and confirmed the benefits of the digital storytelling process for survivors of trauma and those affected by mental illness (Shea, 2010).

The late Jo Carson's *Spider Speculations* (Carson, 2008) shifted my own understanding of the nature of story and the potential for healing in individuals, communities and societies and has deeply influenced the way I think and talk about the shape of stories and the need for a 'dragon', for it was here that I first encountered the immortal words of Flannery O'Connor:

'No matter what form the dragon may take, it is of this mysterious passage past him, or into his jaws, that stories of any depth will always be concerned to tell....' (O'Connor, 1969)

I have interpreted O'Connor's discussion of the dragon as an essential component of any story that is worthy of hearing to be the challenge that is faced by the hero or heroine of the story – the illness, the accident, the despair, the grief, the loss – that must be overcome in order for the hero or heroine to demonstrate his or her courage, strength, wit, wisdom, kindness, resourcefulness or whatever quality it is that contributes to that person's humanity.

There is no shortage of dragons in Patient Voices workshops, and this recognition has given us the opportunity to experience the inextricable link between suffering and compassion as seen through the lives of our storytellers. Repeatedly, we watch as storytellers craft their stories, face their dragons and overcome them, often transforming their views of themselves and their situations. Brené Brown's work on the links between courage and vulnerability has illuminated the transformational experiences of many Patient Voices storytellers, helping them to recognize the heroic nature of their lives and their stories (Brown, 2012).

3.7 Compassion and mindfulness

When the Patient Voices Programme began in 2003, neither stories nor compassion were in vogue. Indeed, an early critical friend warned us against using the word 'compassion' in our *Rationale* (Hardy, 2004). So it was with delight that I found, in 2004, a book written by an American doctor and a Tibetan lama that set out to make Buddhist teachings available and accessible to a western medical audience. Based on research that indicated the decline in

compassion in doctors and healthcare providers as they progressed from medical school into practice, and searching for a way to halt this trend, *Medicine and compassion: A Tibetan Lama and an American Doctor on How to Provide Care with Compassion and Wisdom* (Nyima and Shlim, 2004) offered the perfect justification for the work of Patient Voices as well as an opportunity for me to assimilate a long-standing Buddhist practice with the work of transforming healthcare, a few people at a time.

My own approach to digital storytelling facilitation is grounded in mindfulness, the ancient Buddhist tradition more recently defined as ‘paying attention in a particular way; on purpose, in the present moment and non-judgmentally’ (Kabat-Zinn, 1990). Although mindfulness has achieved acclaim and popularity on its own, my own practice, and that of many other Buddhist practitioners, is supported by Buddhist ethical principles, commonly expressed as The Five Precepts (Nhat Hanh, 1993). These ethical principles provide the foundation for the work of Patient Voices.

Every Patient Voices workshop also embodies the Buddhist concept of ‘interbeing’ (Nhat Hanh, 1988), as individuals gain insight into their shared humanity, and recognise that they are not alone with their suffering, but part of a larger community in which suffering can be transformed into understanding and compassion.

3.8 Epistemic injustice

‘One of the hardest things in life is having words in your heart that you can’t utter.’ (Jones, 1931-)

Although I had never heard the term when Patient Voices began (indeed, I do not think it had been invented in 2003), I knew that the voices and stories of patients and carers were accorded less respect and credibility than the voices of the medical profession. Many Patient Voices stories attest to the failure of medical and health professionals to pay heed to the warnings and concerns of patients, preferring to rely on their professional knowledge and expertise at the expense of the expertise of patients and carers. Havi Carel’s book *Illness* (Carel, 2008) alerted me to the concept of epistemic injustice and I recognised that this was precisely one of the issues we had set out to address through the use of digital stories to give a voice to patients and carers. Epistemic injustice arises from prejudice against certain groups of people, resulting in a reduction in their credibility (Fricker, 2009). Typically, this pertains to women, people from black and minority ethnic backgrounds, people affected by mental illness or learning disability, patients...The consequences can be

serious when, for example, a patient or carer is not believed (Carel, 2012) (Fricker, 2009). But the creation of a story, which is attributed to the storyteller/author, and referenced in a traditionally acceptable way, seems to accord greater respect to the storyteller, whether the storyteller is a patient or a medical student who has not, previously felt listened to (Hardy, 2014).

3.9 The politics of listening and participatory media practice

In the mid-1980s, I became involved with the Society of Friends (Quakers); with their emphasis on stillness and deep listening, the Quakers provided the perfect support and complement to my work with homeless and unemployed people. Through my work at the YMCA Actionline and in attempts to understand the people with whom I was working, I participated in a series of listening skills workshops held at Friends House in London. There, I came across a slender pamphlet called *Creative Listening*, written by a medical doctor who was also a Quaker (Pinney, 1970). Rachel Pinney's contention was that, if we are able to listen really deeply and whole-heartedly, without interrupting or judging, without seeking to find the best response but simply to understand, it would be possible to transform our relationships, our communities and our world. To a naturally quiet person, and one who wanted to bring about transformation, this presented a very appealing possibility.

A decade later I was involved with Zen Master Thich Nhat Hanh's Community of Interbeing where the practice of deep listening and mindful speaking was central to the activities of the community and regarded as a fundamental means of transformation. Careful listening is also fundamental in digital storytelling workshops, particularly in the Story Circle, in order to hear the words that are not spoken as well as those that are, as a way of understanding what the story is *really* about and letting the storyteller know that his or her story is important.

The politics of listening in relation to digital storytelling has been articulated by Darcy Alexandra in her work with undocumented immigrants (Alexandra, 2008) and, more recently, building on the work of Nick Couldry and others (Couldry, 2010) to explain the need for deep listening as an exemplar practice in all stages of the digital storytelling production process (Alexandra, 2015). Listening is also a fundamental and respected element of the American StoryCorps project, which collects and presents the stories of ordinary Americans via National Public Radio; its practice is celebrated by StoryCorps founder Dave Isay in *Listening is an Act of Love* (Isay, 2007).

Participatory media production and participatory media research rely on the participation of citizens, consumers, students or end-users in 'collecting, reporting, analyzing and disseminating content' (https://en.wikipedia.org/wiki/Participatory_media#cite_note-wemedia-1)

Amy Hill, Aline Gubrium and Darcy Alexandra, among others, have been champions of digital storytelling as participatory media practice with special emphasis on the ethical aspects of digital storytelling (Gubrium et al., 2014) (Gubrium and Harper) (Alexandra, 2013).

The ethical considerations in relation to Patient Voices digital storytelling practice will be more thoroughly considered in Chapter 5.

3.10 Summary

The influences on Patient Voices' practice of digital storytelling in healthcare are numerous. Since the earliest days of the Programme, I have read widely and deeply in order to integrate a conceptual and theoretical understanding of the breadth of this work into Patient Voices' everyday principles and practice. This chapter has sought to highlight some of the key influences on my own work and that of the Patient Voices Programme.

References

- Alexandra, D. 2008. Digital storytelling as transformative practice: Critical analysis and creative expression in the representation of migration in Ireland. *Journal of Media Practice*, 9.
- Alexandra, D. 2013. *Visualizing Voice, Embodied Objects, and Implicating Practice: Applied Visual Anthropology in Ireland*. PhD, Dublin Institute of Technology (DIT)
- Alexandra, D. 2015. Are we listening yet? Participatory knowledge production through media practice: Encounters of political listening. In: Gubrium, A., Harper, K. & Otanez, M. (eds.) *Participatory visual and digital research in action*. Walnut Creek, CA: Left Coast Press.
- Baldwin, C. 2005. *Storycatcher : making sense of our lives through the power and practice of story*, Novato, Calif.: New World Library.
- Barrett, H. 2006. Researching and evaluating digital storytelling as a deep learning tool. *TECHNOLOGY AND TEACHER EDUCATION ANNUAL*, 1, 647.
- Batalden, P. B., Nelson, E. C., Edwards, W. H., Godfrey, M. M. & Mohr, J. J. 2003. Microsystems in health care: Part 9. Developing small clinical units to attain peak performance. *Jt Comm J Qual Saf*, 29, 575-85.
- Bauby, J.-D. 1997. *The Diving Bell and the Butterfly*, London: Fourth Estate.
- Boud, D., Keogh, R. & Walker, D. 1985. *Reflection: Turning experience into learning*, London: Kogan Page.

- Brown, C. B. 2012. *Daring greatly : how the courage to be vulnerable transforms the way we live, love, parent, and lead*, New York, NY: Gotham Books.
- Broyard, A. 1992. *Intoxicated by my illness : and other writings on life and death*, New York: C. Potter.
- Carel, H. 2008. *Illness: the art of living*, London: Routledge.
- Carel, H. 2012. Patient voices: Illness and epistemic injustice. *Transforming the patient experience*. Kings Fund, London.
- Carper, B. A. 1978. Fundamental patterns of knowing in nursing. *Advances in nursing science*, 1, 13-24.
- Carson, J. 2008. *Spider speculations : a physics and biophysics of storytelling*, New York: Theatre Communications Group.
- Chamberlin, J. E. 2006. *If this is your land, where are your stories? Finding common ground*, Manchester: Carcanet.
- Charon, R. 2001. Narrative medicine: A model for empathy, reflection, profession, and trust. *JAMA*, 286, 1897-1902.
- Couldry, N. 2010. *Why voice matters: Culture and politics after neoliberalism*: Sage publications.
- Coulter, A., Entwistle, V. & Gilbert, D. 1999. Sharing decisions with patients: is the information good enough? *BMJ*, 318, 318-22.
- Dewey, J. 1938. *Experience and education*, New York: Collier.
- DH. 2000. The NHS Plan: a plan for investment, a plan for reform. *In*: Health, D. O. (ed.). Norwich: HMSO.
- DH. 2001. The expert patient : a new approach to chronic disease management for the 21st century. Great Britain: Department of Health.
- DH. 2002. The Department of Health's response to the Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995. *Norwich: Stationery Office*, 136.
- Donaldson, L. 2003. Expert patients usher in a new era of opportunity for the NHS. *British Medical Journal*, 326, 1279.
- Flanagan, J. C. 1954. The critical incident technique. *Psychological bulletin*, 51, 327.
- Freire, P. 1973. *Education for critical consciousness*: Continuum.
- Freire, P. 2000. *Pedagogy of the oppressed*: Continuum.
- Fricke, M. 2009. *Epistemic injustice : power and the ethics of knowing*, Oxford: Oxford University Press.
- Gandhi, M. 1869-1948. Source of quote unknown.
- Greenhalgh, T. 2006. *What Seems to Be the Trouble?: Stories in Illness and Healthcare*: Radcliffe Publishing.
- Greenhalgh, T. & Hurwitz, B. 1998. *Narrative based medicine : dialogue and discourse in clinical practice*, London: BMJ Books.
- Greenhalgh, T. & Hurwitz, B. 1999. Narrative based medicine: why study narrative? *BMJ*, 318, 48-50.
- Gubrium, A. & Harper, K. *Participatory visual and digital methods*.

- Gubrium, A. C., Hill, A. L. & Flicker, S. 2014. A Situated Practice of Ethics for Participatory Visual and Digital Methods in Public Health Research and Practice: A Focus on Digital Storytelling. *American Journal of Public Health*, e1-e9.
- Haigh, C. & Hardy, P. 2011. Tell me a story—a conceptual exploration of storytelling in healthcare education. *Nurse education today*, 31, 408-411.
- Hardy, P. 2002. SESAME Study Guide. Chelmsford: Anglia Polytechnic University.
- Hardy, P. 2004. *Patient Voices: the rationale* [Online]. Cambridge, UK: Pilgrim Projects. Available: <http://www.patientvoices.org.uk/about.htm> [Accessed].
- Hardy, P. 2007. *An investigation into the application of the Patient Voices digital stories in healthcare education: quality of learning, policy impact and practice-based value*. MSc in Lifelong Learning MSc dissertation, University of Ulster.
- Hardy, P. 2014. Insights into epistemic : hearing from patients and staff. *Perceptions of bullying and undermining behaviour*. Newcastle: Health Education North East.
- Hardy, P. & Redfern, L. 1997. Threads of reflection and the patterns they weave.
- Hurwitz, B., Greenhalgh, T. & Skultans, V. 2004. *Narrative research in health and illness*, Malden, Mass. ; Oxford: BMJ Books.
- IoM. 2001. *Crossing the quality chasm : a new health system for the 21st century*, Washington, D.C. : National Academy Press.
- Isay, D. 2007. *Listening is an act of love : a celebration of American life from the StoryCorps Project*, London New York: Penguin Press.
- Jamissen, G. & Skou, G. 2010. Poetic reflection through digital storytelling—a methodology to foster professional health worker identity in students.
- Johns, C. & Graham, J. 1996. Using a reflective model of nursing and guided reflection. *Nurs Stand*, 11, 34-8.
- Jones, J. E. 1931-. Source of quote unknown.
- Kabat-Zinn, J. 1990. *Full catastrophe living: using the wisdom of your body and mind to face stress, pain and illness*, New York: Dell.
- Kennedy, I. 2001. *The Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995*: Stationery Office.
- Kolb, D. A. 1983. *Experiential learning: Experience as the Source of Learning*, Hemel Hempstead: Prentice-Hall.
- Lorig, K. R., Ritter, P., Stewart, A. L., Sobel, D. S., Brown Jr, B. W., Bandura, A., Gonzalez, V. M., Laurent, D. D. & Holman, H. R. 2001. Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Medical care*, 39, 1217-1223.
- McDrury, J. & Alterio, M. 2003. *Learning through storytelling in higher education: Using reflection and experience to improve learning*, London: Kogan Page.
- Moon, J. 2004. *Handbook of reflective and experiential learning: Theory and Practice*, Abingdon: Routledge and Falmer.
- Nelson, E. C., Batalden, P. B., Huber, T. P., Mohr, J. J., Godfrey, M. M., Headrick, L. A. & Wasson, J. H. 2002. Microsystems in health care: Part 1. Learning from high-performing front-line clinical units. *Jt Comm J Qual Improv*, 28, 472-93.

- Nhat Hanh, T. 1988. *The Heart of Understanding: commentaries on the Prajnaparamita Heart Sutra*, Berkeley: Parallax Press.
- Nhat Hanh, T. 1993. *For a future to be possible: commentaries on the five wonderful precepts*, Berkeley: Parallax Press.
- Nyima, C. & Shlim, D. 2004. *Medicine and compassion: A Tibetan Lama and an American Doctor on How to Provide Care with Compassion and Wisdom*: Wisdom Publications.
- O'Connor, F. 1969. *Mystery and manners; occasional prose*, New York,: Farrar.
- Page, B. 2004. What they really really want. *Health Service Journal*, 114, 16-19.
- Palmer, P. J. 1983. *To know as we are known*, New York: Harper & Row.
- Pennebaker, J. W. 1997. Writing about emotional experiences as a therapeutic process. *Psychological science*, 8, 162-166.
- Pinney, R. 1970. *Creative listening. (Revised edition.)*, Loddington: Creative Listening.
- Sackett, D. L. Evidence-based medicine. *Seminars in perinatology*, 1997. Elsevier, 3-5.
- Schön, D. 1987. *Educating the reflective practitioner: toward a new design for teaching and learning in the professions*, San Francisco: Jossey-Bass.
- Schön, D. 1988. Coaching Reflective Teaching. In: Erickson, G. L. & Grimmett, P. P. (eds.) *Reflection in Teacher Education*. New York: Teachers College Press.
- Shea, M. 2010. *An exploration of personal experiences of taking part in a digital storytelling project*. MSc MSc dissertation, Sheffield Hallam.
- Smith, M. 2001, 2009. Facilitating learning and change in groups. *The encyclopaedia of informal education* [Online]. Available: www.infed.org/mobi/facilitating-learning-and-change-in-groups-and-group-sessions/.
- Smith, M. K. 2002. *Malcolm Knowles, informal adult education, self-direction and andragogy* [Online]. Available: www.infed.org/thinkers/et-knowl.htm [Accessed].
- Sontag, S. 1990. *Illness as metaphor ; and, AIDS and its metaphors*, New York: Doubleday.
- Stanton, P. 2004. *The Strategic Leadership of Clinical Governance in PCTs*: NHS Modernisation Agency.
- Thompson Long, B. 2014. *Designing digital storytelling: creative technology for reflection in initial teacher education*. PhD, National University of Ireland.
- Tripp, D. 1993. *Critical incidents in teaching*, London: Routledge.
- Wenger, E. 1999. *Communities of practice: learning, meaning and identity*, Cambridge: Cambridge University Press.
- Wilcock, P. M., Brown, S., Ceri, G., Bateson, J., Carver, J. & Machin, S. 2003. Using patient stories to inspire quality improvement within the NHS Modernization Agency collaborative programmes. *Journal of clinical nursing*, 12, 422-430.
- Winterson, J. 2007. *The stone gods*, London: Hamish Hamilton.

Chapter 4: Introduction to the publications and the narrative

'As always in history, statistics give little insight into individual experience. That can only be gained by listening to stories.' (Rees, 2005)

4.1 Introduction

In this chapter I will introduce and comment on the peer-reviewed publications that are included in this thesis, explaining how they have developed the work of the Patient Voices Programme and expanded the body of knowledge in relation to digital storytelling.

4.2 List of publications and their context in this thesis

The eight publications and the website are described and set in context below.

4.2.1 Adapting digital storytelling for use in healthcare: history, ethics and distribution

The Journey Begins

First do no harm: developing an ethical process of consent and release for digital storytelling in healthcare

Patient Voices: the website www.patientvoices.org.uk

4.2.2 Digital storytelling in healthcare education

Tell me a story: a conceptual exploration of storytelling in healthcare

Challenging the shock of reality through digital storytelling

Physician know thyself: using digital storytelling to promote reflection in medical education

4.2.2 Digital storytelling with patients and people

Our stories ourselves: exploring identities, sharing experiences and building relationships through Patient Voices

Dangling conversations: reflections on the process of creating digital stories during a workshop with people with early stage dementia

Digital storytelling with users and survivors of the UK mental health system

4.3 The Journey Begins

'Every journey begins with a single step.' Lao Tzu

This is the first chapter in the first book to be written about digital storytelling in healthcare: *Cultivating Compassion: how digital storytelling is transforming healthcare*, edited by Tony Sumner and myself. The book was produced as a celebration of the first ten years of the Patient Voices Programme and consisted of a collection of chapters written by healthcare academics, educators and practitioners who had commissioned Patient Voices workshops. This chapter describes the conception and early development of the Patient Voices Programme, situating it in its historical, educational, technological social and healthcare context, and setting out our aspirations for digital storytelling in healthcare. The chapter sets the scene for the rest of the book, which goes on to consider the development of the Patient Voices Programme and establishes the value of digital storytelling in healthcare in the following contexts:

- Patient involvement, quality improvement and impact of the stories
- Transformational learning
- The healing power of digital storytelling
- The evidence of experience
- A model for co-production.

4.4 First do no harm: developing an ethical process of consent and release for digital storytelling in healthcare

This paper was published in *Seminar.net*, a peer-reviewed, online, open access journal, in 2015. The paper sets out the history and theory behind the development of the three-stage consent and release process that has been used by the Patient Voices Programme in an attempt to address the complex set of issues presented by the creation and dissemination of personal stories that include images as well as voice. Since the earliest days of the Programme, we knew it was necessary to protect our storytellers and ourselves. With the help of the first two Patient Voices storytellers, a consent form was created that formed a two-way, mutually beneficial contract and established the principles under which Patient Voices stories would be licensed and released. Since then, the process has been developed and refined to ensure that protection from harm is carefully balanced with the potential

benefits of the process and publication of the stories. The paper can be accessed here:

<http://www.seminar.net/volume-11-issue-3-2015>

4.5 Patient Voices: the website www.patientvoices.org.uk

The Patient Voices website was established to ensure free distribution and wide visibility of the stories that are created in Patient Voices workshops. Once approved by the storyteller, stories are released under a Creative Commons 2.5 licence which stipulates that they must not be sold or changed and they must be attributed. Under this licence, they are freely available for viewing and use by anyone, anywhere in the world. The website is the window through which stories and other activities of the Patient Voices Programme may be viewed and represents a significant body of work.

4.6 Tell me a story: a conceptual exploration of storytelling in healthcare

This paper was published in *Nurse Education Today*. It begins with a consideration of the use of stories in education before exploring the use of storytelling in healthcare and healthcare education, considering some of the skills and benefits to be derived from storytelling and then speculating on the potential offered by new technologies, including digital storytelling, especially in relation to stories told by patients and carers. The paper concludes that benefits of stories and storytelling seen in education generally are readily transferable to healthcare and healthcare education. Importantly, the paper draws attention to the value of stories told by patients and carers as an important addition to the stories told by students and educators, and notes the potential of digital storytelling as a means of making this possible. This paper therefore contributes to the theoretical foundation of the work of the Patient Voices Programme.

4.7 Challenging the shock of reality through digital storytelling

This paper was published in *Nurse Education in Practice* in 2011. It describes an educational development with newly-qualified mental health nurses that aimed to illuminate the often-challenging experiences of nurses as they transition from the relative safety of the academic environment to the harsher reality of clinical practice. This phenomenon is well-documented in the literature and has become known as a 'reality shock' (Kramer, 1974). The impact of this shock has implications for quality of care, post-qualification support strategies, practitioner well-being and attrition rates.

The project, based on a Patient Voices reflective digital storytelling workshop, aimed to illuminate the experiences of newly-qualified nurses through the creation of reflective digital stories about a difficult experience they had faced; the stories were then used to offer other student nurses opportunities to reflect on and consider strategies that might help them cope with the challenge of transition; the digital stories were also used with educators and preceptors to consider approaches that would enable them to better facilitate appropriate preparation for and adaptation to the world of clinical practice.

The paper concluded that the stories offered viewers (both students and educators) a unique opportunity to walk in the shoes of the storyteller and, in so doing, provide opportunities for different stories to be told, stories about building resilience and maintaining the capacity to care.

‘The Spiral of Growth Through Stories’ model (based on Kolb’s learning cycle) was developed to demonstrate the potential of digital stories to be used as a new model of learning for individuals as well as communities of learners, preceptors and others engaged in the education and practice of healthcare. Stories from this project can be seen here:

www.patientvoices.org.uk/un.htm

4.8 Physician know thyself: digital storytelling with medical students

This book chapter has been accepted for publication in *Digital Storytelling in Higher Education: International Perspectives*, to be published by Palgrave Macmillan early in 2017. The chapter describes a project undertaken with third year medical students at Kings College London (KCL), one of the largest medical schools in Europe.

A Student Selected Component (SSC) at KCL was created as a means of offering medical students a different way to learn about reflection while also developing self-awareness and emotional intelligence. A pilot project was set up during which third year medical students created digital stories about an experience in their clinical placements that had particularly touched them.

The stories that the students created revealed high levels of self-awareness and, in particular, the recognition that their patients are not simply collections of symptoms but rather people in distress who are in need of kindness and consideration just as much as they are in need of clinical interventions. The medical students all commented on the

importance of this realisation and its impact on their future as clinicians, supposing that they would be more humane doctors as a result of making their digital stories.

The implications of the project are that digital storytelling with students of healthcare has the potential not only to increase their capacity for creative reflection, but also to increase self-awareness, deepen insight, strengthen professional identity and contribute to a more humane approach to both medical education and the practice of medicine. The stories created during the project can be seen here: www.patientvoices.org.uk/pkt.htm

4.9 Our stories ourselves: exploring identities, sharing experiences and building relationships through Patient Voices

This chapter was included in *Community-Based Multi-Literacies and Digital Media Projects: Questioning Assumptions and Exploring Realities*, published by Peter Laing in 2014. The expansion of the digital world in the 21st century requires the acquisition of new literacies, those that enable people to think, learn, teach, communicate, explore, socialise and conduct business in a digital world. For many people, the acquisition of these essential skills is through community projects. However, although much has been written about the projects themselves, much less has been explored through the eyes of the researchers, scholars, community workers, organisers and practitioners involved in setting up and running these projects. The book sets out, therefore, to consider the issues, challenges and successes at 'personal, local and global levels' and their implications for practice and theory in multi-literacy and digital media projects' (Pleasants and Salter, 2014). The book consists of five parts:

- 1 The ethics and politics of representation and 'doing good'
- 2 Identities and relationships
- 3 Methodologies
- 4 Pedagogies and knowledge constructions
- 5 After the project

This chapter was located in Part 2 of the book and, while touching on some of the issues that form the focus of the other parts (including ethical and methodological issues, it confirms that 'there is more that unites us than divides us', highlighting the commonalities across identities and experiences that are revealed by the stories of patients, carers and

clinicians, and considering the opportunities for more compassionate relationships that are created by bearing witness to the stories.

4.10 Dangling conversations: reflections on the process of creating digital stories during a workshop with people with early stage dementia

This paper was published in 2012 in the *Journal of Psychiatric and Mental Health Nursing*. The paper reports on a workshop in which people with dementia created digital stories. It is based upon the daily reflections of the four workshop facilitators and focuses on the adaptations to the usual Patient Voices workshop process that were necessary in order to help people with failing memories participate as fully as possible in the creation of their digital stories.

The digital storytelling workshop was set up in response to a need to help student nurses develop the capacity for compassionate care and to provide a balance for the empirical knowledge that dominates most nursing and medical curricula by offering the student nurses an opportunity to engage creatively with the experience of dementia.

The workshop provided the opportunity for seven people with early stage dementia to create digital stories that would then be incorporated into an e-learning package for student nurses. Although the storytellers faced considerable challenges in developing their stories, all felt that they benefited from the process which was both creative, person-centred and empowering, with the intention of fostering self-expression and a sense of identity. The paper concludes that this way of working with people affected by dementia could serve as a model for more engaged participation in their care and a greater sense of well-being. The stories created in the workshop can be seen here:

www.patientvoices.org.uk/dc.htm

4.11 Digital storytelling with users and survivors of the UK mental health system

This is a book chapter accepted for inclusion in *Story, Form and Content in Digital Storytelling: Telling Tales* due to be published by Palgrave Macmillan early in 2017. The book sets out to bring together an international group of digital storytelling practitioners and researchers to explore how stories are found, told and understood within the context of self-representation and digital culture.

Our chapter in this book sets out to reveal some of the issues and challenges we have faced when working with people affected by mental illness, as well as some of the rewards and lessons learned from working with such vulnerable people. Most importantly, we have become aware of the value of looking after ourselves in order to ensure the emotional safety of the storytellers; this has meant a commitment to cultivating self-awareness as well as a commitment to regular supervision. A number of other adaptations are discussed that have ensured that we can provide the necessary attention, deep listening and non-judgemental acceptance that people with severe mental illness need in order to feel safe enough to express themselves and share their stories. The results have been tangible and rewarding at both personal and organisational level with storytellers reporting increased confidence and catharsis, while the organisation has seen a reduction in complaints and clinical negligence claims since using the stories in a variety of ways to increase awareness of what really matters to its patient and carer population.

4.12 Summary

In this chapter, I have set out a list of the publications that are included in this thesis together with a brief description of each one. The first two publications (*The journey begins* and *First, do no harm*), describe the historical and ethical foundations of the Patient Voices Programme while the third presents the Patient Voices website as the vehicle for free distribution of the stories.

I then considered some of the theoretical justification for the use of storytelling in healthcare and healthcare education in the third publication (*Tell me a story*) and followed this with two papers (*The shock of reality* and *Physician, know thyself*) that examine the use of digital storytelling with newly-qualified nurses and medical students. In both projects, the process of digital storytelling was used to offer an opportunity for deep reflection; in the first, the product of this reflection, i.e. the stories, became objects of reflection for student nurses and educators. For the medical students, the creation of the stories was an end in itself but served to create a stronger sense of identity and a more humane and compassionate approach to patients.

The seventh publication (*Our stories, our selves*) examines the potential of digital storytelling to contribute to the development of individual identity and, at the same time, to promote a greater appreciation for the importance of community, communication and compassion.

In the last two publications (*Dangling conversations* and *Digital storytelling with users and survivors of the UK mental health system*), I considered some of the challenges that we have faced when working with people whose capacity is limited, either intellectually, emotionally, technologically and/or physically - in this case, people affected by dementia, and by mental illness. The chapters describe some of the adaptations that have had to be made in order to facilitate the creation of the digital stories and explain some of the realisations we have had about ourselves as digital storytelling facilitators, including our own need for support and supervision.

References

- Kramer, M. 1974. Reality shock: Why nurses leave nursing. *AJN The American Journal of Nursing*, 75, 891.
- Pleasants, H. M. & Salter, D. E. 2014. *Community-Based multiliteracies and digital media projects: questioning assumptions and exploring realities*, New York: Peter Lang.
- Rees, L. 2005. *Auschwitz : a new history*, New York: Public Affairs.

Chapter 5: Adapting digital storytelling for use in healthcare: history, ethics and distribution

‘Stories promote empathy, which in turn prompts reflection and serves as the motivation for learning and acquiring new knowledge.’

(Charon and Montello, 2002)

5.1 Introduction

This chapter focuses on the conception and growth of the Patient Voices Programme as a pioneering and innovative experiment in the use of digital stories and digital storytelling in healthcare, healthcare education and e-learning. In adapting digital storytelling for use in these contexts, a number of issues had to be addressed, particularly in relation to technology, methodology and ethics. The publications included in this chapter demonstrate the ways in which I have broken new ground by adapting digital storytelling for use in the world of healthcare and addressed the complex issues around ethical consent and release that have supported the successful development of the Patient Voices Programme. The three publications are:

1. *The journey begins*
2. *First do no harm: developing an ethical process of consent and release for digital storytelling in healthcare*
3. *The Patient Voices website*

The first paper explains how I adapted digital storytelling for use in healthcare and healthcare education by describing the early development of the Patient Voices Programme. The second paper describes the development of the ethical consent and release process that is used to protect Patient Voices storytellers and their stories, while ensuring the suitability of their stories for public release. The Patient Voices website is the public expression of our commitment to free distribution of the Patient Voices stories.

5.2 The journey begins

I conceptualised the idea of using digital stories in healthcare education in 2003 after seeing a digital story created as part of a community history project. Having been involved in

distance, open and online education for a number of years, I knew that the best way to help students connect with empirical content was to enable them to connect with aesthetic, moral and personal aspects of what they needed to know (Carper, 1978; Salzberger-Wittenberg et al., 1999). As far as it was possible to determine, no one else was using digital storytelling in healthcare or healthcare education; nor was anyone else using digital storytelling in online learning programmes. With the aspiration of using stories to transform healthcare through the vision of the Patient Voices Programme, we set out on a journey with no map and very few signposts.

The journey begins describes how we set out on that journey and covers the first few years of Patient Voices' pioneering work in developing and adapting digital storytelling for use in healthcare, healthcare education and e-learning.

Note: The second edition of *Cultivating Compassion: How Digital Storytelling is Transforming Healthcare* will be published by Palgrave Macmillan in the summer of 2017. The first edition is no longer available.

5.3 Ethical issues in relation to digital storytelling in healthcare

One of the essential – and distinguishing – features of the Patient Voices Programme has been our focus on ethics. We were guided by our first storytellers to develop a reciprocal consent procedure and we drew on Buddhist ethical principles promoting respect for life, property, speech, reputation and community (Nhat Hanh, 1993), ethical guidelines supporting biomedical research and the need for autonomy, beneficence, non-maleficence and justice (Beauchamp and Childress, 2009) as well as the principles of justice, respect, equity and trust underpinning clinical governance to ensure that our work would result in the greatest possible good with the least possible harm. In an invited publication exploring the use of digital storytelling in health and social care, I discussed how ethical considerations were woven into the work of Patient Voices and explained how we attempted to work according to these ethical principles: ‘in order to protect storytellers and their stories, we wrap the safe and supportive workshop process in a two-stage process of informed consent that ensure that control of the story edit and release remains with the storyteller’ (Hardy and Sumner, 2008). The two-stage process evolved, eventually to a three-stage process, acknowledging the vulnerability of many storytellers and allowing more time to reflect on how they would like their stories to be used.

Patient Voices’ ethical process has undergone regular review, adaptation and development over the years. There is little visible evidence of other initiatives aimed at developing codes of ethical practice for applied digital storytelling, other than Amy Hill and Aline Gubrium ‘s work in health promotion and with survivors of trauma, which has resulted in a code of ethical practice for digital storytelling facilitators (Gubrium et al., 2012). Our work on ethics has been acknowledged by the international digital storytelling community and I have spoken about our ethical process at a number of national and international conferences, for example, in Cardiff, Ankara and via an online webinar for Alberta Health Services (Hardy, 2013a) (Hardy, 2013c) (Hardy, 2013b).

First do no harm: developing an ethical process of consent and release for digital storytelling in healthcare describes the development of this process and considers the fine balance that must be achieved when working with vulnerable people and using image and voice, while still remaining committed to the principles of acknowledgement and free access to the stories.

The paper is available from <http://seminar.net/volume-11-issue-3-2015>

5.4 The Patient Voices website: www.patientvoices.org.uk

'Digital storytelling empowers patients, carers and clinicians to convey their felt experiences of healthcare via technology so that their voices can be heard in any lecture theatre, Board room or conference venue anywhere in the world.' (Hardy, 2007)

The Patient Voices website is the public face of our work. From the outset of the Patient Voices Programme, we were committed to ensuring that the effort and courage of storytellers would result in the maximum social capital and that their voices would be heard; this relied on free distribution of the stories that had been created. The Patient Voices website was established in 2004. Our intention to curate a freely-available collection of digital stories about healthcare was innovative then and the website is still thought to be the largest repository of freely-available digital stories about healthcare in the world. At the time of writing there are ~700 stories on the website, as well as a selection of our presentations and publications.

5.4.1 Facts and figures

By 2008, there was growing interest into how, where and when the stories were being used. So we gathered some data and the following statistics were first presented at the NET conference (Hardy, 2008).

Variations in monthly usage over a year

In the 12 months leading up to and including September 2008, the website received in the region of 350,000 hits per year and approximately 89GB of data were downloaded.

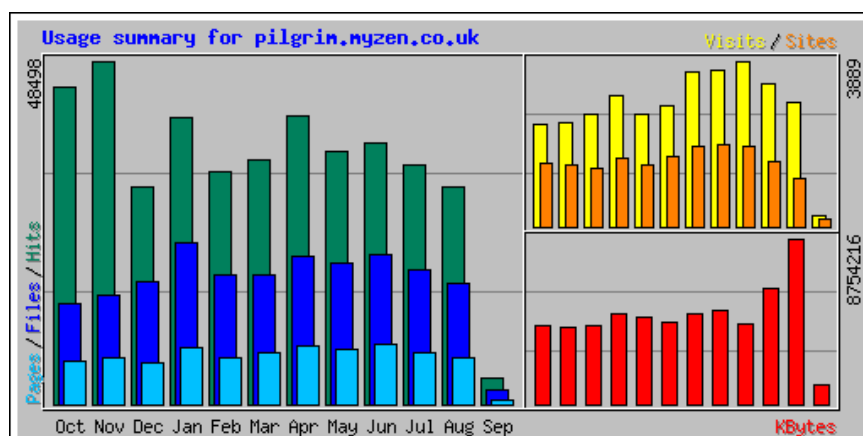


Figure 5.1 Patient Voices website usage by number of hits from October 2007 through August 2008.

In the 12 months leading up to August 2016, as Figure 5.2 shows, the website received approximately 1,029,743 hits and approximately 248GB of data were downloaded; this represents an increase of approximately 225%.

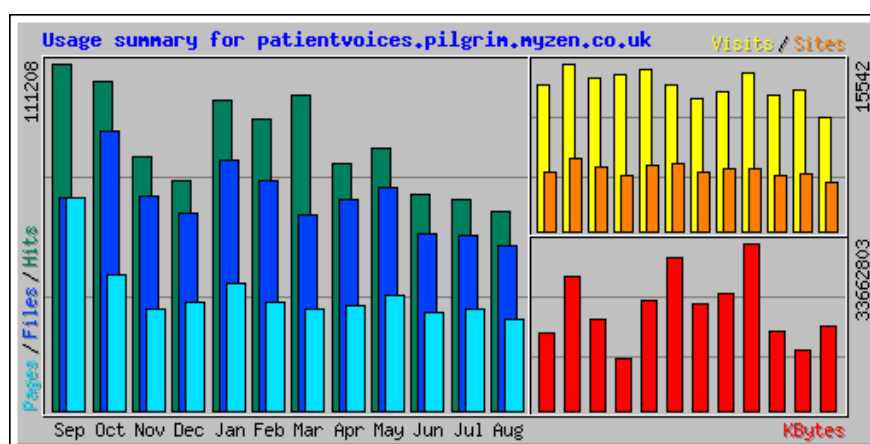


Figure 5.2 Patient Voices website usage by number of hits from September 2015 through August 2016

We can also see that website usage shows peaks in September/October and March, potentially correlating with the start of academic semesters.

Breakdown of usage by domain in one month

Figure 5.3 shows a breakdown of usage by domain; not surprisingly the UK is the largest consumer of data from the website, followed by .com domains which, although largely associated with US commercial organisations, may also include some UK users.

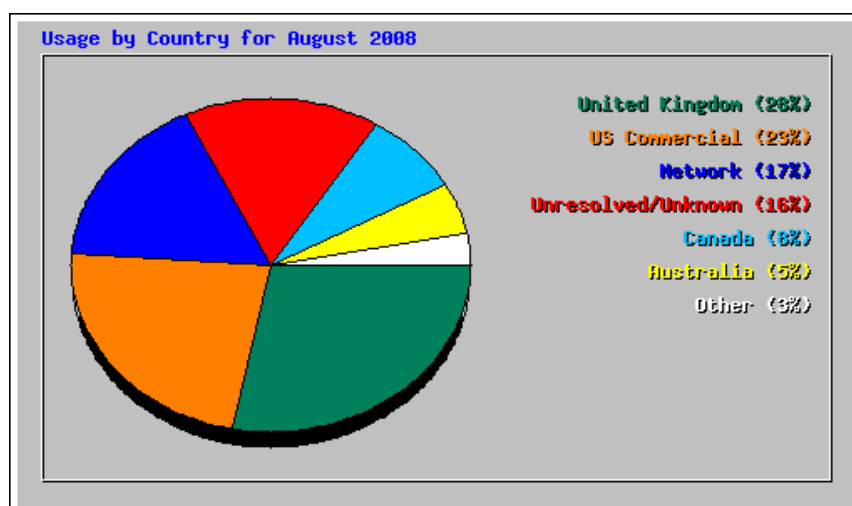


Figure 5.3 Patient Voices website usage by domain in August 2008

In August 2016, we can see that .com domains are still the largest consumers of data from the website; it is likely that 'unknown' domains also include many UK users. Notable now is the inclusion of Australia and Germany as significant consumers of data.

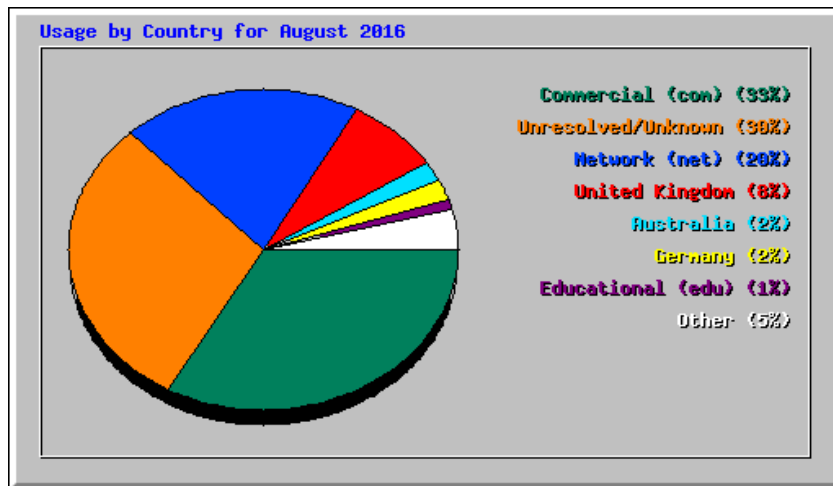


Figure 5.4 Patient Voices website usage by country for August 2016

Variations in hourly usage averaged over one month

Figures 5.5 and 5.6 show the change in hourly usage from 2008 to 2016

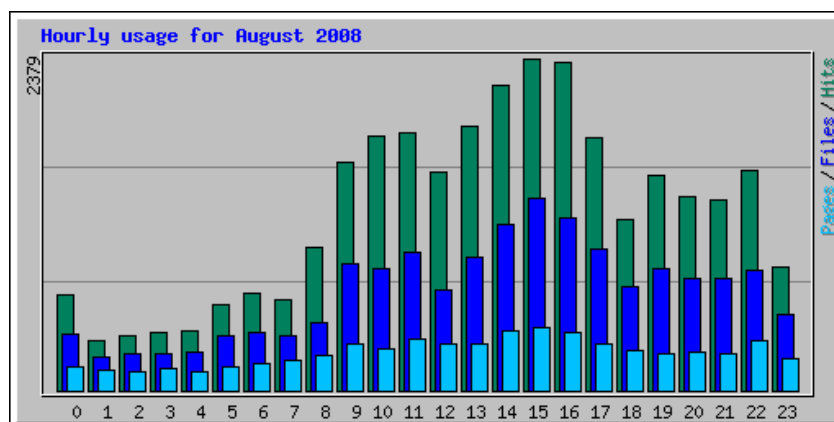


Figure 5.5 Patient Voices website hourly usage in August 2008

In 2008, hourly usage over the day shows three distinct phases:

Phase 1: midnight (GMT) to approximately 0700 GMT

Phase 2: approximately 0700 GMT to approximately 1600

Phase 3: from approximately 1700 GMT to approximately 2300 GMT

Phase 2, which shows the highest usage, correlates with daylight hours in the UK.

Phase 3, which shows an intermediate level of usage correlates with daylight hours in North America

Phase 1, which shows the lowest usage, would appear to correlate with other time zones.

This breakdown would appear to correlate with time zones that correspond to English-speaking countries. The majority of the stories on the Patient Voices are created within the UK and the Programme itself is UK-based, so it is not surprising that the highest usage of the website is within the UK; equally it is not surprising that the second highest user would appear to be one of the geographical areas where English is the first language.

By 2016, although usage is still greatest during the UK working day, it is more evenly spread throughout the 24 hours, indicating that website traffic is coming from more different countries in different time zones.

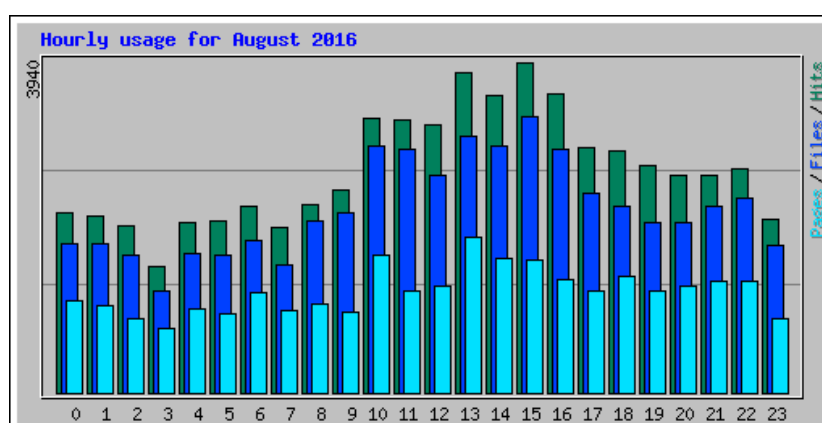


Figure 5.6 Patient Voices website hourly usage in August 2016

Annual summary of traffic month by month

Figure 5.7 provides a summary of traffic to the website over the course of one year. September 2015 was the month with the highest number of hits, followed closely by October 2015, once again correlating with the start of academic semesters in the UK and North America.

Summary by Month										
Month	Daily Avg					Monthly Totals				
	Hits	Files	Pages	Visits	Sites	KBytes	Visits	Pages	Files	Hits
Aug 2016	2651	2199	1211	437	4545	16874528	10489	29078	52796	63627
Jul 2016	2175	1804	1060	421	5311	12253073	13080	32860	55933	67439
Jun 2016	2310	1886	1045	418	5186	15871939	12552	31354	56601	69308
May 2016	2711	2299	1186	472	5812	33662803	14643	36794	71288	84059
Apr 2016	2647	2254	1121	431	5788	23591703	12954	33644	67639	79432
Mar 2016	3265	2023	1053	394	5454	21518895	12240	32644	62723	101242
Feb 2016	3228	2546	1205	468	6293	30743780	13578	34962	73860	93624
Jan 2016	3205	2593	1316	485	6033	22219516	15061	40797	80393	99376
Dec 2015	2376	2038	1130	468	5086	10645087	14531	35031	63203	73685
Nov 2015	2714	2295	1081	471	5922	18446146	14139	32443	68874	81444
Oct 2015	3396	2895	1399	501	6723	26913983	15542	43382	89759	105299
Sep 2015	3706	2270	2275	450	5413	15598399	13512	68261	68110	111208
Totals						248339852	162321	451250	811179	1029743

Figure 5.7 Summary of traffic by month

Over the past eight years, website activity has steadily increased and there is now a steady flow of traffic throughout the year and from around the world with more than 200GB of data downloaded during the past year.

5.4.2 Who uses the stories and how do they use them?

Every light was a story and the flashes themselves were the stories going out over the waves, as markers and guides, comfort and warning.’ (Winterson, 2004)

The majority of Patient Voices stories are created in small workshops commissioned by an organisation that has a particular use for the stories that will be created in the workshop. However, due to the model of free distribution and the intention to build social capital with the stories, uses of the stories are as many and varied as are the people who choose to use them in their lectures, seminars, conference presentations, e-learning programmes, workshops, etc.. Research conducted for my masters revealed that the stories were valued for their ‘brevity, flexibility and veracity’ (Hardy, 2007). This flexibility, as well as the wide-ranging impact of the stories, has continued to be borne out by the comments and emails we receive from people who have, for example, used a story that was created as part of a patient safety programme, in a lecture about health inequalities (Mauchland, 2006).

The range of organisations with which we have worked is extensive, ranging from small local and national charitable organisations to large, multi-national philanthropic institutions; equally extensive is the wide variety of ways in which the stories have been used, ranging from team-building to guideline implementation, from prompting discussions about complex issues such as health inequality to programme evaluation. A list of clients and uses of the stories is included in Appendix 1.

5.5 Summary

In this chapter, I have demonstrated the innovative nature of the Patient Voices Programme, its contribution to healthcare education and to the world of digital storytelling, and the expansion of its influence via the website. I have described the ways in which careful attention to a complex range of issues has resulted in the wide distribution and successful use of digital stories and digital storytelling in healthcare and have shown that the Patient Voices approach to technology, methodology, ethics and distribution has not only given a voice to people who would not otherwise be heard, but has also had a

significant impact on healthcare education as well as on the theory and practice of digital storytelling around the world.

References

- Beauchamp, T. L. & Childress, J. F. 2009. *Principles of biomedical ethics*, New York ; Oxford: Oxford University Press.
- Carper, B. A. 1978. Fundamental patterns of knowing in nursing. *Advances in nursing science*, 1, 13-24.
- Charon, R. & Montello, M. 2002. *Stories Matter: The Role of Narrative in Medical Ethics (Reflective Bioethics)*: Routledge.
- Gubrium, A., Hill, A. L. & Harding, L. 2012. *Digital Storytelling Guidelines for Ethical Practice, including Digital Storyteller's Bill of Rights* [Online]. Berkeley, CA: StoryCenter. Available: <https://www.storycenter.org/s/Ethics.pdf> [Accessed November 2015].
- Hardy, P. 2007. *An investigation into the application of the Patient Voices digital stories in healthcare education: quality of learning, policy impact and practice-based value*. MSc in Lifelong Learning MSc dissertation, University of Ulster.
- Hardy, P. 2008. 'Do not go softly into that good night': giving patients a voice through digital storytelling. In: Hardy, P. (ed.) *NET 2008*. Cambridge UK.
- Hardy, P. 2013a. 'First do no harm': ethical issues in digital storytelling. *DS8*. Cardiff, UK.
- Hardy, P. 2013b. First do no harm: ethical issues in digital storytelling. *Create Act Change: The International Digital Storytelling Conference*. Ankara, Turkey.
- Hardy, P. 2013c. Making the big picture personal: opportunities, challenges and some ethical issues. Online webinar: Alberta Health Services.
- Hardy, P. & Sumner, T. 2008. Digital storytelling in health and social care: touching hearts and bridging the emotional, physical and digital divide. *Lapidus Journal*.
- Mauchland, B. 2006. *Jimmy's story* [Online]. Cambridge: Pilgrim Projects Limited. Available: <http://www.patientvoices.org.uk/flv/0047pv384.htm> [Accessed March 2014].
- Nhat Hanh, T. 1993. *For a future to be possible: commentaries on the five wonderful precepts*, Berkeley: Parallax Press.
- Salzberger-Wittenberg, I., Williams, G. & Osborne, E. 1999. *The Emotional Experience of Learning and Teaching*, London: Karnac.
- Winterson, J. 2004. *Lighthousekeeping*, London Harper Perennial, 2004 (2005 printing).

Chapter 6: Digital storytelling in healthcare education

‘Educating the mind without educating the heart is no education at all.’

Aristotle

6.1 Introduction

Storytelling is one of the most ancient – and most human – of activities. Stories help us make sense of the world and enable us to learn the things that are necessary in order to survive in families, clubs, schools, organisations, societies and cultures – ‘the things we know, but do not necessarily know we know’ (Linde, 2001; Hardy and Jaynes, 2011). Stories can bring about changes in culture (Hardy, 1990) and offer learning opportunities to those who will listen and heed. Good teachers offer their students stories to stimulate creativity, promote critical thinking, exercise the imagination, prompt reflection, encourage moral reasoning and learn from mistakes – all essential aspects of high quality healthcare.

The Patient Voices stories are intended to bring greater humanity into healthcare education, encouraging students to see patients as people, often with a great deal of expertise in their own conditions. It seems that the stories often stimulate greater creativity and imagination among educators, who report that it is possible to teach a whole session (or even several sessions) based on one story, such is the engagement of the students and their eagerness to discuss the issues that arise (Wareham, 2006). Another interesting situation arose when a team from the Royal College of Nursing were prompted to reconsider their education strategy once they had seen the stories that had been created. They moved from initially wanting the stories to meet particular learning outcomes to:

‘rethink their education curriculum around clinical governance and continence care in order to “develop education around the stories, trying to get people to think about specific situations rather than conditions, treating patients as individuals, rather than treating conditions.”’(p24) (Hardy, 2007)

Digital stories enable viewers walk in someone else’s shoes for just a few minutes, providing deep insights, promoting greater understanding and empathy and offering the possibility of learning and change, going beyond clinical, technical skills and empirical knowledge to include moral, aesthetic and personal ways of knowing (Carper, 1978). The publications in this chapter demonstrate the impact of the Patient Voices Programme on,

and show how I have used digital storytelling and digital stories to bring about change in, healthcare and healthcare education.

This chapter includes three publications:

1. *Tell me a story: a conceptual exploration of digital storytelling in healthcare*
2. *Challenging the shock of reality through digital storytelling*
3. *Physician know thyself: using digital storytelling to promote reflection in medical education*

The first of these papers provides a conceptual basis for the use of stories in healthcare and healthcare education, arguing, in particular, for the use of patient (and carer) stories to augment the stories told by students and staff. The second paper describes a project that was designed to explore how digital storytelling with newly qualified mental health nurses could contribute to understanding the reality shock that is experienced during the transition from education to practice. The third paper looks at how digital storytelling was used with medical students to promote deep reflection.

6.2 Tell me a story: a conceptual exploration of digital storytelling in healthcare

'We tell stories to entertain and to teach.' (Attributed to Pascal)

This publication explores the potential, and justifies the use, of digital stories and digital storytelling in healthcare and demonstrates the contribution I have made to educational theory through the intentional use of stories in healthcare, both traditional and digital.

The paper was innovative at the time of writing, not only proposing the use of digital stories as a useful means of engaging students, promoting empathy and prompting reflection, but also extending the customary storytelling role beyond educators and students to patients, carers and service users.

According to Google Scholar, the paper has had 72 citations, in articles ranging from the use of new technology to engage students, through articles extolling the use of stories in professional education and using storytelling to effect change at individual as well as organisational level (Drumm, 2013) to articles specifically utilising digital storytelling to promote reflection in healthcare students.

The paper is available here:

www.sciencedirect.com/science/article/pii/S0260691710001486

.3 Challenging the shock of reality through digital storytelling

The phenomenon known as ‘reality shock’ arising from the transition between nurse education and clinical practice (Kramer, 1974) is widely recognised. It has a negative impact on newly qualified nurses’ wellbeing, compassion and ability to care with humanity and kindness, as well as on attrition rates. In order to reduce the impact of this shock, different kinds of education and support strategies are necessary. This paper shows how digital storytelling can reduce the impact of the shock and also contribute to the development of strategies for educators and preceptors to use to prepare and support students and newly qualified nurses during the transition.

The new ‘The spiral of growth through stories’ model was developed, building on and extending Kolb’s experiential learning cycle (Kolb, 1983), highlighting the potential of stories to promote learning and growth and bringing about change in individuals and groups.

The paper illuminates the contribution I have made, not only to the literature about digital storytelling but also to the literature and learning about reflection and reflective practice; it also demonstrates how digital storytelling and digital stories can improve the quality of students’ experience while contributing to strategies for more appropriate pre-qualification and post-qualification support.

The paper is available here:

www.sciencedirect.com/science/article/pii/S1471595310001071

6.4 Physician, know thyself: using digital storytelling to promote reflection in medical education

This publication is a chapter in a book entitled *Digital Storytelling in Higher Education: International Perspectives*. The aim of this book is to broaden the scope and impact of digital storytelling in higher education. Through a collection of chapters written by international academics, researchers and practitioners, the book seeks to describe and explain how we may teach, research and build communities in higher education and use digital storytelling to develop relations with the professions, workplaces and civil society. The intention is to demonstrate how digital storytelling may offer solutions to important issues that higher education is confronting in terms of relevance, significance and vocation for students, teachers and the civil society. This use of digital media is considered in the light of the analytical pattern developed by the Carnegie foundation for the advancement of teaching: the four scholarships. The argument that telling stories digitally may improve the capacity of higher education to teach better, to improve research, to enhance the meaning making of higher education to students as well as building better and more collaborative relations with society at large, is then explained in the sections.

This is the only chapter in the book that focuses on medical education and considers, specifically, the value of digital storytelling as a means of helping medical students achieve the goal of the scholarship of teaching and learning by 'extending and transforming their knowledge' (Boyer, 1994). Despite the small scale of the project, the successful outcomes of the educational experiment described in the chapter have implications that extend beyond medical education to healthcare education and beyond.

The book in which this chapter appears will be published by Palgrave Macmillan in 2017 and is available here: <http://www.palgrave.com/gb/book/9783319510576>

The events and the learning described in *Physician, Know Thyself* illustrate the potential of digital storytelling to bring about the kind of personal transformation and deep learning that emerge from an epistemological shift in a student's frame of reference; in other words, through the practice of digital storytelling, students not only look at (or reflect on) events and ideas from their own perspectives, but they also look at how they are looking (or reflecting) as part of a process of discovery (Mezirow, 1997).

6.5 Summary

In this chapter, I have presented three papers that demonstrate my approach to digital storytelling in healthcare education. The first paper set out the theoretical foundation for the use of stories in healthcare education, while the second two papers describe storytelling projects with newly-qualified nurses and medical students respectively, showing that the process of creating digital stories can contribute to the ability to reflect deeply on practice, to the development of greater resilience, to the potential for personal and organisational transformation, and to an awareness of the need for more humane, compassionate, person-centred care.

References

- Boyer, E. L. 1994. *Scholarship reconsidered: priorities of the professoriate*, Princeton, NJ: The Carnegie Foundation for the advancement of teaching.
- Carper, B. A. 1978. Fundamental patterns of knowing in nursing. *Advances in nursing science*, 1, 13-24.
- Drumm, M. 2013. The role of personal storytelling in practice. *Insights*. Scotland.
- Hardy, P. 2007. *An investigation into the application of the Patient Voices digital stories in healthcare education: quality of learning, policy impact and practice-based value*. MSc in Lifelong Learning MSc dissertation, University of Ulster.
- Hardy, P. & Jaynes, C. 2011. Editorial: Finding the voices for quality and safety in healthcare: the never-ending story. *Journal of Clinical Nursing*, 20, 1069-1071.
- Hardy, R. 1990. *Callback : NASA's Aviation Safety Reporting System*, Washington, D.C.: Smithsonian Institution Press.
- Kolb, D. A. 1983. *Experiential learning: Experience as the Source of Learning*, Hemel Hempstead: Prentice-Hall.
- Kramer, M. 1974. Reality shock: Why nurses leave nursing. *AJN The American Journal of Nursing*, 75, 891.
- Linde, C. 2001. Narrative and social tacit knowledge. *Journal of Knowledge Management*, 5.
- Mezirow, J. 1997. *Transformative learning in action: insights from practice*, San Francisco, CA: Jossey-Bass.
- Wareham, D. 2006. *RE: Conversation*.

Chapter 7: Digital storytelling with patients and people

‘The solitary human being is a contradiction in terms and therefore you seek to work for the common good because your humanity comes into its own in belonging.’ Archbishop Desmond Tutu

7.1 Introduction

Although the practice of digital storytelling is firmly rooted in community theatre and community development, in the third edition of *Digital Storytelling: Capturing Lives, Creating Community*, Joe Lambert comments that issues of health and well-being, illness, accident and loss were never far from the work of Story Center (Lambert, 2012).

Nevertheless, Patient Voices was the first digital storytelling initiative to ‘develop extensive healthcare work in digital storytelling’ (Lambert, 2012). In an interview with Joe that forms a chapter in the above-mentioned book, we set out our aspiration for bringing digital storytelling to healthcare:

‘Our hope was that by bringing the very human element of stories back into healthcare education and service improvement programmes, we could contribute to the huge task of humanising a healthcare system that was increasingly characterised by targets and checkboxes, audits and statistics. We often have said that “statistics tell us the system’s experience of the individual, whereas stories tell us the individual’s experience of the system.”’
(Hardy and Sumner, 2010) (Lambert, 2012).

Traditionally, in healthcare, the experiences of patients or service users were conveyed quantitatively by means of statistics, reports, audits, and so on. The digital storytelling methodology adopted and adapted for use by the Patient Voices Programme offered an innovative and qualitative way of bringing these experiences – these stories – to the attention of the people who needed to understand them in order to design and deliver healthcare that was safe, effective and humane; our commitment to free distribution of released stories ensured that the stories would be seen by as many of these people as possible.

In our attempts to ‘heal’ the health system, we have also seen healing aspects of digital storytelling with many, if not most, of the individuals with whom we have worked. While this phenomenon is not unique to Patient Voices, the groups of people with whom we work

are likely to be more severely affected by mental and physical illness, impairment and disability or facing significant challenges, socially, intellectually, physically or technologically. This has required us to be agile, adaptive and aware in our facilitation methods and has stretched the classical digital storytelling model to its limits while, at the same time, ensuring that we meet each and every storyteller not as a 'patient', or a 'carer', or someone with a particular condition, but as a person, with unique and individual qualities as well as universal and human qualities.

Paradoxically, the uniqueness of every individual is also what makes us most human and the uniqueness of every story that makes it universal in its humanity. It is precisely this paradox that the Patient Voices Programme has recognised, revealed and celebrated through more than 1000 stories that have been created during Patient Voices' lifetime.

As a vehicle for social justice, digital storytelling is intended to enable ordinary people to share their stories but a brief literature search suggests that our work with people facing severe challenges to health and wellbeing is unusual, even in the world of digital storytelling. Our approach to working with people affected by dementia and by mental illness has been ground-breaking and I have presented at a number of national and international conferences, including keynotes in Norway, (Hardy and Sumner, 2012), Brighton (Sumner and Hardy, 2013) and London (Hardy and Sumner, 2013) about how we have worked with people facing these particular challenges and highlighting the changes that come from creating their digital stories.

This chapter offers insights into the Patient Voices workshop process; considers some of the challenges when working with certain groups of people, describes the adaptations that have enabled these people to participate as fully as possible in the creation of their digital stories and highlights the benefits and rewards of digital storytelling not only for storytellers but also for facilitators. The three publications included in this chapter are:

1. *Our stories ourselves: exploring identities, sharing experiences and building relationships through Patient Voices*
2. *Dangling conversations: reflections on the process of creating digital stories during a workshop with people with early stage dementia*
3. *Digital storytelling with users and survivors of the UK mental health system*

The first publication looks at the ways in which Patient Voices has contributed to the development of personal identity, to greater self-awareness and, in many cases, to

transformation. The second publication considers the challenges posed by working with people with dementia and the adaptations that were necessary in order to represent their stories as honestly as possible. The third publication discusses a five-year project undertaken with people affected by mental illness and looks at the ways in which we have worked to ensure their safety as well as our own.

7.2 Our stories ourselves: exploring identities, sharing experiences and building relationships

‘People reach greater maturity as they find the freedom to be themselves and to claim, accept and love their own personal story, with all its brokenness and its beauty.’ (Vanier, 2004)

Patients are people long before they are patients. And yet their identity is closely bound up with their illness and many face epistemic injustice – the experience of having less credibility simply by being a patient (Fricker, 2009; Carel and Kidd, 2014). This chapter questions some of the conventional assumptions that are made about patients, explores the realities of working with people who are patients as well as people and highlights the ways in which I have attempted to break down the barriers that separate the ‘ill’ from the ‘well’, exploring how the way we work with people facilitates shifts in understanding and in identity.

Community-based Multiliteracies & Digital Media Projects: Questioning Assumptions and Exploring Realities, the book in which this chapter appears, is available here:

<https://www.peterlang.com/view/product/29951>

7.3 Dangling conversations: reflections on the process of creating digital stories during a workshop with people with early stage dementia

‘An important challenge to humanity is to recognise that lives are the pasts we tell ourselves.’ (Ochs and Capps, 1996)

The classical model of digital storytelling encourages reflection on the part of facilitators as well as storytellers. When working with people facing challenges such as dementia, who may not be capable of reflecting for themselves, it is even more important for the facilitators to engage in ongoing reflection – what Donald Schön described as ‘reflection-in-action- and ‘reflection-on-action’ (Schön, 1983). This paper describes the way we, as facilitators, adapted our approach and the workshop methodology to suit people affected by dementia. Regular reflection sessions at the end of each day enabled us to become (and remain) aware of our own processes and thus able to adapt to the needs of the storytellers to enable them to tell the stories they needed – and wanted – to tell.

The stories that were created were incorporated into an e-learning programme designed to promote the cultivation of aesthetic knowledge, emotional intelligence and compassion; a screen grab is provided below. An evaluation of the project indicated that, although students engaged with the digital stories at some level, there was a need for facilitation of reflection and deeper engagement (Haigh et al., 2012).

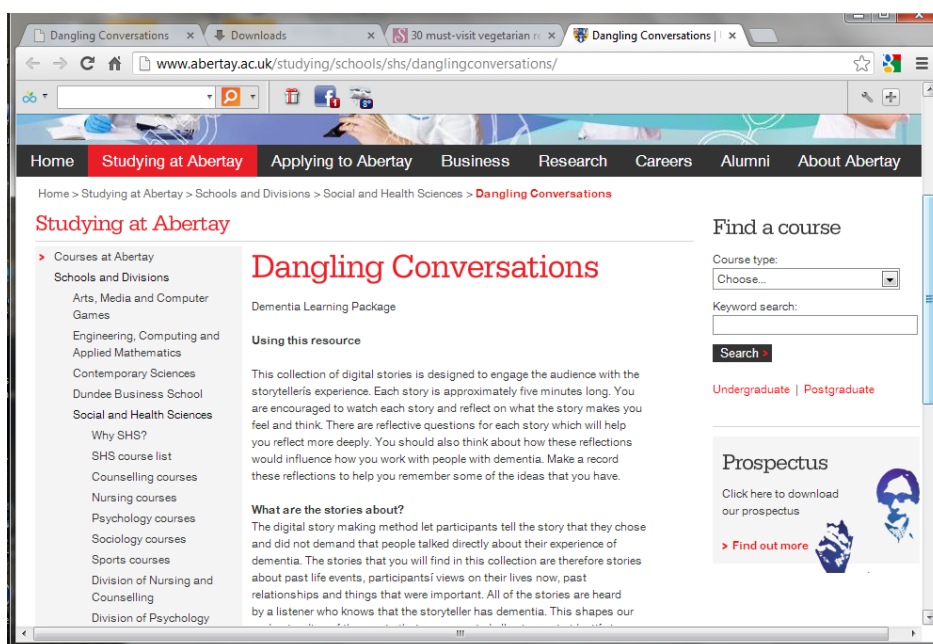


Figure 7.1: Screen grab of Dangling Conversations e-learning course, accessed 24th May 2013

The project was featured on a BBC radio programme and has been presented at several international conferences, including an invited keynote at the 'Meeting with Memories' conference in Norway (Hardy and Sumner, 2012) and a symposium at the NET 2012 conference in Cambridge, UK (Haigh et al., 2012).

Several storytellers commented, some weeks after the workshop, that the workshop process had been so helpful. One man, who had great difficulty speaking (due to his dementia), was, with great delight, able to speak with greater fluency than for many years; he commented 'I feel like me again!'

The innovative nature of this project enabled people who would not otherwise be heard to have a voice, to know that their experiences and opinions matter, and to influence the next generation of nurses who will care for them. As a direct result of the 'Dangling Conversations' project, we have been invited to facilitate other workshops with people affected by dementia, such as the 'Dementia Insights' project in Lancashire; the stories from that project have, in turn, led to the development of an early diagnosis campaign in Lancashire. The stories have also led to increased awareness within the council of the need to work with people with dementia in order to adapt both the built environment and the planning systems that control the built environment to the needs of people with dementia. There have continued to be presentations about our work with people with dementia, including at the Faculty of Public Health annual conference in 2016 (Atcha and Hardy, 2016).

The Dangling Conversations stories can be seen here: www.patientvoices.org.uk/dc.htm

The Dementia Insights stories can be seen here: www.patientvoices.org.uk/di.htm

This paper can be found here: <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2850.2012.01900.x/full>

7.4 Digital storytelling with users and survivors of the UK mental health system

This book chapter offers readers an inside view into what it's like to work with people affected by mental illness. The work itself, conducted during 11 workshops over nearly five years, has had a significant impact on the organisation and the way it engages with service users and carers. The project was innovative in several ways: the first innovation was offering an opportunity for service users in this organisation to tell their own stories in their own ways; the second is in the steps we have taken to ensure our own safety and wellbeing and the third innovation is the way in which the stories themselves have resulted in reductions in complaints and clinical negligence claims (Haigh et al., 2013).

At the time of writing, the book containing this chapter has not yet been published so it is not possible to comment on the impact of the publication. However, the Manchester work has been presented a number of times, including a (virtual) presentation at the Summit for Global Mental Health in South Africa (Hardy, 2011) and at the Global Mental Health Conference at the London School of Hygiene and Tropical Medicine (Hardy and Sumner, 2013).

The discussion in relation to the need for supervision for facilitators is likely to resonate with digital storytelling facilitators who find themselves working with people affected by trauma, abuse and/or mental health issues. Our approach to this aspect of our work is one important way in which I continue to contribute to the developing professionalism of digital storytelling facilitation.

The stories created in Manchester can be seen here: www.patientvoices.org.uk/dandr.htm and here: www.patientvoices.org.uk/workingtogether.htm

Story, Form and Content in Digital Storytelling: Telling Tales, the book in which this chapter appears, will be published by Palgrave Macmillan in the summer of 2017.

<http://www.palgrave.com/>

7.4 Summary

As facilitators, we have a wide range of skills to underpin our digital storytelling work. This is matched by our emphasis on reflection. Daily reflections by facilitators and storytellers allow us to be aware of our own facilitation process and how this is working for storytellers; this awareness enables us to draw on the particular skills needed to adapt to the needs of the storytellers in the group. A further, final, reflective session at the end of each workshop (after all showing the stories) further reinforces the learning and change that have occurred during the workshop and provide important information for us that may lead to future adaptations.

My own training in psychodynamic counselling and group work enables me to recognise the crucial link between the safety and wellbeing of storytellers and the safety and wellbeing of the facilitators, which led, in turn, to initiating regular, formal supervision sessions with an experienced counselling supervisor.

In this chapter I have demonstrated how the Patient Voices Programme has offered an innovative way for people who are patients to convey their experiences, other than by the traditional route of surveys, questionnaires and interviews. I have shown how we have worked to break down traditional barriers and adapt our facilitation approach in ways that empower people to tell the important stories that often result in transformation, both of individuals and of groups while ensuring the safety and security of both storytellers and facilitators. The Patient Voices methodology and Patient Voices stories have been adopted by a number of NHS (and other) organisations (please see Appendix 1), who have recognised the value of both the stories and the storytelling process for their patient and carer populations.

References

- Atcha, Z. & Hardy, P. 2016. Digital storytelling by people with dementia: melting hearts and minds with the evidence of experience. *Public Health in a Cold Climate: Melting Hearts and Minds with Evidence*. Brighton, UK.
- Carel, H. & Kidd, I. J. 2014. Epistemic injustice in healthcare: a philosophical analysis. *Med Health Care Philos.*
- Fricker, M. 2009. *Epistemic injustice : power and the ethics of knowing*, Oxford: Oxford University Press.
- Haigh, C., Cahoon, P. & Sumner, T. 2013. Working with dignity and respect: improving mental health services. In: Hardy, P. & Sumner, T. (eds.) *Cultivating compassion: how digital storytelling is transforming healthcare*. Kingsham Press.

- Haigh, C., Hardy, P., Kenny, A. & Stenhouse, R. 2012. Hearing Voices: creating and using digital stories of mental health to promote dignity, humanity and compassion in healthcare and healthcare education. *NET 2012*. Cambridge UK.
- Hardy, P. 2011. Hearing Patient Voices: Hearing and Recovery through Digital Storytelling. *Global Mental Health Summit*. Capetown, South Africa (virtual presentation).
- Hardy, P. & Sumner, T. 2010. Humanizing healthcare: A conversation with Pip Hardy and Tony Sumner, Pilgrim Projects/Patient Voices. In: Lambert, J. (ed.) *Digital Storytelling: Capturing Lives, Creating Community*. third ed. Berkeley, California: Digital Diner Press.
- Hardy, P. & Sumner, T. 2012. Dangling conversations: stories of dementia. *Meeting memories*. Oslo, Norway: Oslo City Museum.
- Hardy, P. & Sumner, T. 2013. Hearing voices: transforming cultures. *Global Mental Health Exhibition*. London School of Hygiene and Tropical Medicine.
- Lambert, J. 2012. *Digital storytelling : capturing lives, creating community (3rd edition)*, New York ; London: Routledge.
- Ochs, E. & Capps, L. 1996. Narrating the Self. *Annual Review of Anthropology*, 25, 19-43.
- Schön, D. 1983. *The reflective practitioner: How professionals think in action*, New York: Basic books.
- Sumner, T. & Hardy, P. 2013. Dangling conversations: digital storytelling - age, vocation and value. *Silver Stories Launch*. Brighton, UK.
- Vanier, J. 2004. *Drawn into the mystery of Jesus through the Gospel of John*, New York: Paulist Press.

Chapter 8: Summary and conclusions

'In my end is my beginning.'

'We shall not cease from exploration

And the end of all our exploring

Will be to arrive where we started

And know the place for the first time.' (Eliot, 1959)

8.1 Overview

This thesis set out to document the growth of digital storytelling in healthcare and examine the contribution of the Patient Voices Programme to the wider emergent genre of digital storytelling. I have presented eight publications and a website all relating to my work as architect and co-founder of the Patient Voices Programme. These submissions have covered a range of topics and issues and highlight how digital storytelling in healthcare was pioneered and has developed through Patient Voices. I have considered in particular:

- the early history of Patient Voices and digital storytelling in healthcare
- ethical issues that have arisen and been addressed to support the work of Patient Voices
- development of the Patient Voices website and its impact on healthcare education and service improvement
- the contribution of Patient Voices digital stories and digital storytelling in healthcare education
- the innovative way in which Patient Voices has enabled patients and people to present 'the evidence of experience'
- the adaptations made to the classical digital storytelling model in order to support patients facing particular challenges or with particular needs.

8.2 Contribution to new knowledge

Chapter 5 describes the inception and development of the Patient Voices Programme, explains the ethical foundations of the Programme and introduces the website, which is the means by which the Patient Voices digital stories are made accessible to the world.

Chapter 6 provides a theoretical foundation for the use of stories and storytelling in healthcare education and describes the innovative ways in which digital stories and digital storytelling have had an impact on healthcare education, particularly with respect to developing reflective practice and supporting students and newly qualified practitioners. This showed how digital storytelling is used in healthcare education to promote deep reflective practice, develop emotional intelligence and resilience, cultivate empathy and compassion, exercise moral judgement and moral imagination and understand the need for greater humanity in healthcare.

Chapter 7 turned to the ways in which the Patient Voices Programme offered a new way for patients and people to share their experiences of care (and sometimes the lack of it) in order to illuminate what really matters to them. Chapter 7 also explored the impact of the digital storytelling process and described certain adaptations and innovations made to ensure that the storytelling process is as beneficial, productive and safe as possible for facilitators and storytellers alike. This process of exploration, fuelled by humility as well as curiosity, is ongoing, and continues to contribute to what might be considered a new kind of knowledge, one that embraces being and becoming, authenticity and autonomy, confidence and competence, compassion and community, self-awareness and empathy, ethics and emotional intelligence, responsibility and resilience.

8.3 Themes of the thesis

A number of themes were introduced in Chapter 3 that have informed the development of the Patient Voices Programme and my understanding of digital storytelling; these were:

- Reflection
- Transformational learning
- Holistic, emancipatory and transformational education
- Healthcare quality improvement and the patient experience
- Stories, narrative and the humanities in healthcare

- Compassion and mindfulness
- The healing power of stories
- Epistemic injustice
- The politics of listening and participatory media practice.

These themes are woven throughout the thesis; they underpin the way Patient Voices' digital storytelling practice has developed and the many ways the stories are used to bring about learning and change. This thesis has shown how new knowledge has been created in a number of different arenas, summarised below.

8.3.1 Using stories to understand the patient experience

It was not until around the turn of the century that there was any significant recognition that high quality healthcare relies on understanding the needs and experiences of those who receive care. Gathering this intelligence traditionally relied on evidence gathered from surveys and presented as reports, graphs, charts and statistics. The use of stories in the field of healthcare quality improvement was, in the early 21st century, considered to be a novel way of gathering this intelligence (Wilcock et al., 2003) although the use of stories was beginning to be appreciated (Charon, 2006) (Greenhalgh and Hurwitz, 1999).

The Patient Voices Programme was founded with the express intention of providing a balance to statistical evidence and offering a different way of understanding the patient experience through the stories told by the people receiving care.

8.3.2 Using storytelling to deepen reflective practice

The use of stories as a way of making meaning, sharing knowledge, engaging audiences and promoting empathy is well documented (Bruner, 1986) (Charon, 2001). The use of digital storytelling, however, offers new opportunities to engage students and qualified clinicians with deep reflection (Jamissen and Skou, 2010) (Skarpaas et al., 2016). With the original aim of using stories to prompt reflection in viewers in the hope of stimulating reflection on practice (Hardy, 2004), I found that the process of creating stories was an even more effective way to deepen reflection on practice, while also contributing to greater self-awareness and the development of professional identity.

8.3.3 A solid ethical foundation

Underpinning all aspects of my work with Patient Voices is a commitment to the highest ethical standards. The ethical process designed for use in Patient Voices is intended to provide safety and security for storytellers while ensuring that their stories are also safe to be released to the public. We believe that the innovative model of free distribution that is underpinned by this ethical foundation was unique at the time it was originated and remains unusual. The process has remained responsive, adapting to the needs of storytellers; it has been widely acknowledged in the field and praised by, for example, the National Audit Office and the BBC.

8.3.4 Development and adaptation of digital storytelling methods

Since its foundation, the Patient Voices Programme has developed and adapted the classical model of digital storytelling for use in a variety of contexts within the world of healthcare. As facilitators we have prided ourselves on the awareness, agility, adaptability and responsiveness that have enabled us to work with storytellers aged from 12 to 102, from nuns to murderers, from healthcare assistants to consultants, from people with PhDs to people with no formal education.

8.3.5 Addressing epistemic injustice

Before seeing Patient Voices storytellers as patients or professionals, carers or consultants, we see them as people – people who have important experiences to share. The ethical processes we have designed, together with our adaptive approaches, have ensured that every one of the 1000+ Patient Voices storytellers has been able to tell his or her story to a worldwide audience in his or her own way, knowing that the story will not be changed or altered in any way and with the credibility and visibility their stories deserve. The development of a referencing convention that accords due respect to storytellers also contributes to the value of their experiences and their stories.

8.4 Limitations of the thesis

In a field as broad, as multi-disciplinary and as new as digital storytelling, it would be impossible to cover every aspect; even with respect to digital storytelling in healthcare, the opportunities for research and evaluation are almost endless. This thesis, while attempting to provide an overview has necessarily been limited to a relatively narrow range of exploration, even within the extensive work of the Patient Voices Programme.

Other limitations are in relation to specific age groups; we have not yet had the opportunity to adapt the Patient Voices reflective digital storytelling methodology with children younger than 12. This area could certainly be further explored, particularly with developments in technology that make it increasingly easy for even young children to be creative and reflective.

The publications presented in this thesis are not based on traditional research methods but rather have sought to explain the contribution that I have made to the emerging field of digital storytelling and its application in healthcare. Evaluating one's own work can be problematic and I have attempted to maintain a degree of mindful subjectivity and reflexivity while also sharing what I have learned with the wider community in the hope that this learning will contribute to the development of an approach to digital storytelling that is at once responsible, professional, ethical and capable of bringing about transformation at many different levels.

8.5 Future research

There is ample scope for further research into the uses and impact of digital storytelling in healthcare. One frequently asked question is 'What is the impact of the Patient Voices digital stories?' While I hope that this thesis has demonstrated the impact of the Patient Voices Programme, I believe there is a need to conduct further research into the impact of the stories on practice. There has been some recent evaluation into the impact of the digital stories as part of an educational package for clinicians involved in end of life care, but this approach could be extended and expanded to other clinical areas.

There are also opportunities to explore the use of digital stories in interprofessional education. The current project using digital stories as the basis for an interprofessional education intervention in end of life care will be written up following completion of this thesis. Another project, intended to reveal the inextricable links between staff wellbeing and patient care, has involved digital storytelling with NHS staff to illuminate their experiences in relation to several specific themes, including compassion, wounded healers, leading change, staff as carers and learning from serious incidents. I intend to undertake some evaluation of this project and expect to write up the DNA of Care project.

I would also like to explore further the use of digital storytelling as a therapeutic process, not only for patients but also for healthcare staff. A project is currently being proposed that will evaluate the impact of digital storytelling on a group of young people and their parents

who are affected by serious chronic conditions, in this case, severe multi-system allergies and sickle cell disease; the project team has just received ethics approval to evaluate the Patient Voices workshops.

Another ongoing project (funded by the National Institute for Health Research - NIHR) is in relation to the use of digital stories as the foundation for an educational intervention for people in the African Caribbean community who are affected by schizophrenia. It will be interesting to see the results of this research.

Digital storytelling has been found to be helpful in engaging healthcare students with the reflective processes necessary for them to become competent clinicians, but I would like to explore this in greater depth and, in particular, to discover whether engaging with digital stories and digital storytelling can contribute to the identity formation of clinicians who are more humane, more emotionally intelligent, more resilient and more compassionate.

Finally, a long-term ambition has been to conduct a longitudinal study on a group of students, offering them the opportunity to create a digital story at the beginning of each academic year, from their entry to university until some years after graduation, in an attempt to discover what changes in terms of their goals, aspirations, concerns, fears. I believe this could be of interest to educators, mentors, preceptors and employers.

I hope that completion of this PhD will be one step along a continuing journey of exploration of the uses of digital storytelling and digital stories in healthcare and beyond.

References

- Bruner, J. 1986. *Actual minds, possible worlds*, Cambridge, Mass. ; London: Harvard University Press.
- Charon, R. 2001. Narrative medicine: a model for empathy, reflection, profession, and trust. *Jama*, 286, 1897-1902.
- Charon, R. 2006. *Narrative Medicine: Honoring the stories of illness*, New York: Oxford University Press.
- Eliot, T. S. 1959. *Four Quartets*, London: Faber & Faber.
- Greenhalgh, T. & Hurwitz, B. 1999. Narrative based medicine: why study narrative? *BMJ*, 318, 48-50.
- Hardy, P. 2004. *Patient Voices: the rationale* [Online]. Cambridge, UK: Pilgrim Projects. Available: <http://www.patientvoices.org.uk/about.htm> [Accessed].
- Jamissen, G. & Skou, G. 2010. Poetic reflection through digital storytelling—a methodology to foster professional health worker identity in students.

- Skarpaas, L. S., Jamissen, G., Krüger, C., Holmberg, V. & Hardy, P. 2016. Digital Storytelling as Poetic Reflection in Occupational Therapy Education: An Empirical Study. *The Open Journal of Occupational Therapy*, 4, 20.
- Wilcock, P. M., Brown, S., Ceri, G., Bateson, J., Carver, J. & Machin, S. 2003. Using patient stories to inspire quality improvement within the NHS Modernization Agency collaborative programmes. *Journal of clinical nursing*, 12, 422-430.

Appendix 1: List of clients and intended use of the stories (2003-2016)

Year	Sponsor	Aims of project	Weblink
2010	Anglia Ruskin University	To create stories and share experiences of working in and with multi-professional learning organisations – part of a research project	Stories created for internal use and learning for staff but a presentation about the project is here: www.patientvoices.org.uk/pdf/presentations/AERA%2020130430.pdf
2011	Castle Peak Hospital, Tuen Mun Health Authority, Hong Kong	To facilitate a workshop for senior staff to explore the experience and possibilities of using digital storytelling. To deliver the keynote at their annual quality conference and led a workshop about the work of Patient Voices	Stories created for internal use and learning for staff
2012	Children's Liver Disease Foundation	To facilitate two workshops with young people affected by liver disease to create stories for use in awareness-raising, fund-raising and education	www.patientvoices.org.uk/ttt.htm
2007	Cintra Translation	Stories to offer insight into the experiences and ethical dilemmas of professional interpreters, especially those working in the health sector, for use in interpreter training	www.patientvoices.org.uk/inteps.htm
2007	Connect: the communication disability network	Stories to provide insights into the experiences of people who have had a stroke at a relatively young age and who are, themselves, still engaged in active parenting	www.patientvoices.org.uk/connect.htm
2007	Connecting for Health	To design a conference about the future of nursing and technology, based on our storytelling methodology and resulting in stories that reveal important uses of technology	www.patientvoices.org.uk/cfh.htm
2011	Department of Health	To create stories that highlight the importance of patients getting involved in research	www.patientvoices.org.uk/ppires.htm
2007	Essex Regeneration Agency (ExDRA)	To create stories offering insights into the lives of people living with a range of disabilities (blindness, paralysis, learning disability, etc.) for use in training and teaching	www.patientvoices.org.uk/exdra.htm
2007	Harrogate Carers' Resource	To provide insight into the lives of family carers for people affected by mental or physical illness or disability	www.patientvoices.org.uk/hcr.htm
2015	Health Education North East (HENE)	To create stories about end-of-life care, from the perspective of relatives and clinicians, for use in an interprofessional learning resource for clinicians engaged in EoL care	www.patientvoices.org.uk/ipei-neolc.htm

Year	Sponsor	Aims of project	Weblink
2016	Imperial College Healthcare NHS Foundation Trust	To create stories with young people affected with severe allergies and their parents, and young people with sickle cell disease and their parents for use in education and training	www.patientvoices.org.uk/tt.htm
2009	Isle of Wight Stroke Club	To create stories offering insight into life after stroke and promote service user involvement in stroke service design	www.patientvoices.org.uk/iowsc.htm
2014	Kings College London Medical School	To design and deliver an SSC to teach reflection to medical students, through the creation of digital stories about practice placements	www.patientvoices.org.uk/pkt.htm
2015	Lancashire County Council	To create stories with people affected by dementia and their carers for use in education, training and improvement, including the development of dementia-friendly homes and communities	www.patientvoices.org.uk/di.htm
2010	La Trobe University, Bendigo, Australia	To create stories that explore the meaning of recovery, with consumers/service users and providers of mental health care in order to shape recovery-oriented care	www.patientvoices.org.uk/latrobe.htm
2010	La Trobe University, Bendigo, Australia	To enable first responders in the Victoria bush fires to share their stories of trauma, loss and courage	www.patientvoices.org.uk/bchs.htm
2011	La Trobe University, Bendigo, Australia	To create stories revealing insights into life in rural Australia, as part of the 'Building Healthy Rural Communities' research project designed to promote citizen participation in healthcare design	www.patientvoices.org.uk/hrc.htm
2015	Lancashire County Council	To create stories offering insight into the experiences of people living with dementia for use in training, awareness raising, campaigning and service redesign	www.patientvoices.org.uk/di.htm
2009	Leeds NHS Primary Care Trust	To create stories about the value of patient engagement and involvement, created by involved and engaged patients for use in service improvement initiatives	www.patientvoices.org.uk/leedspect.htm
2011-present	Manchester NHS Mental Health and Social Care Trust	Ongoing project (11 workshops) for service users to create stories about their experiences of mental health services for use in Board meetings, training, recruitment and awareness-raising.	www.patientvoices.org.uk/wr.htm
2010	Motor Neurone Disease Association	To create stories about living with MND and develop an e-learning resource for clinicians working with people affected by MND	www.patientvoices.org.uk/mnd.htm
2006	National Audit Office	To create stories as qualitative data and a DVD to accompany NAO report on Stroke care to demonstrate that people affected by stroke can make good recoveries and lead meaningful lives; stories were also shown at major conference about stroke care and presented to the Public Accounts Committee	www.patientvoices.org.uk/naoconn.htm

Year	Sponsor	Aims of project	Weblink
2007	National Audit Office	To create stories as qualitative data and a DVD to accompany NAO report on the reorganisation of neonatal services and offer insight into the experiences of mothers of premature babies, shown at conferences and be presented to the Public Accounts Committee	www.patientvoices.org.uk/nao_neo.htm
2009	National Audit Office	To create stories as qualitative data and a DVD to accompany NAO report into end of life care, shown at conferences and presented to the Public Accounts Committee	www.patientvoices.org.uk/nao_eol.htm
2003	National Clinical Governance Support Team	Stories to illuminate the values of clinical governance (that is, trust, equity, respect and justice) and were intended for use in presentations to Boards to illuminate 'the patient experience' and also for use in e-learning resources about clinical governance	www.patientvoices.org.uk/ikramer.htm www.patientvoices.org.uk/mclarke.htm www.patientvoices.org.uk/eallen.htm www.patientvoices.org.uk/dclark.htm www.patientvoices.org.uk/aryan.htm www.patientvoices.org.uk/gjdesa.htm www.patientvoices.org.uk/cbruce.htm
2010	National Patient Safety Agency/Royal College of Nursing	To create stories (told by staff) to provide insights into patient safety (or the lack of it) for use in training and safety initiatives	www.patientvoices.org.uk/npsa.htm
2008	Newham Primary Care Trust	To create stories in celebration of the Communities of Health project developed in Newham, revealing the diversity and wisdom of its population for use in training and health promotion	www.patientvoices.org.uk/newham.htm
2012	NHS East London and the City with Homerton University Hospital NHS Trust	To create stories offering insights of people affected by COPD for use in training and service improvement	www.patientvoices.org.uk/easybreathing.htm
2011	NHS Lothian	To create stories about living with COPD and the difference a good telehealth project can make to promote self-management and improved quality of life	www.patientvoices.org.uk/sth.htm
2015	NHS England	To create stories celebrating the accomplishments of people with learning disabilities and offering guidance as to appropriate care and involvement in decision-making	www.patientvoices.org.uk/champions.htm

Year	Sponsor	Aims of project	Weblink
2016	NHS England	To create stories with NHS Staff (five workshops) intended to find out what really matters to them, in acknowledgement of the interconnectedness between the staff experience and the patient experience (The DNA of Care)	www.patientvoices.org.uk/dnaoc.htm
2015	NHS Health Education North East	To create stories with staff as well as family carers to reveal key themes for people involved in end of life care and provide the foundation for an online, interprofessional resource for clinicians working in end of life care	www.patientvoices.org.uk/ipeineolc.htm
2006	NHS Heart Improvement Programme	To create stories with staff and patients celebrating the work of the Heart Improvement Programme	www.patientvoices.org.uk/hip.htm
2014	NHS Improving Quality	To create stories about change as part of the School for Health and Care Radicals	Mostly not released to Patient Voices website, but please see: www.patientvoices.org.uk/flv/0848pv384.htm
2016	NHS Improving Quality	To design and deliver a 1.5 hour 'Edge Talk' webinar about storytelling for transformational change	http://theedge.nhs.uk/thethe-power-of-storytelling-as-a-force-for-transformational-change/
2016	NHS Improving Quality	To teach citizens storytelling, listening and editing skills to enable them to record Citizen Reported Outcomes for use in education, training and service improvement	For internal use
2008	NHS Institute for Innovation and Improvement	To create stories about the experiences of people with diabetes as inpatients for use in service improvement and redesign and as part of the 'Think Glucose' toolkit	www.patientvoices.org.uk/nhsii.htm
2013	NHS Institute for Innovation and Improvement with Barts and the London NHS Trust	Part of the Both Sides Now! Project intended to gather stories from patients and staff about the same issue in order to inform action and improvement – the focus was on safety (Patient Feedback Challenge award)	www.patientvoices.org.uk/comingtogether.htm
2014	NHS Institute for Innovation and Improvement with Manchester Mental Health and Social Care NHS Trust	Part of the <i>Both Sides Now!</i> Project intended to gather stories from patients and staff about the same issue in order to inform action and improvement – the focus was on mental health (Patient Feedback Challenge award)	www.patientvoices.org.uk/workingtogether.htm
2013	NHS Institute for Innovation and Improvement with Princess Alexandra Hospital	Part of the Both Sides Now! Project intended to gather stories from patients and staff about the same issue in order to inform action and improvement – the focus was on learning disability (Patient Feedback Challenge award)	www.patientvoices.org.uk/learningtogether.htm

Year	Sponsor	Aims of project	Weblink
2011	NHS Lothian with the Scottish Centre for Telehealth	To create stories with people with COPD who had taken part in an initiative designed to offer more accessible pulmonary rehabilitation classes by using digital video conferencing	www.patientvoices.org.uk/sth.htm
2004	NHS Modernisation Agency	To design a conference for carers as part of the campaign for greater recognition and improved care for carers, using digital stories as prompts and provocations	www.patientvoices.org.uk/care/rsconf2004.htm
2006	NHS Scotland ISD	To provide consultancy and adapt Patient Voices methodology for use with people homebound with COPD to contribute to service redesign	Stories created for internal use and learning for staff
2006	NHS Tayside	To gather stories that reveal unsafe practices in the hope of promoting safer care	www.patientvoices.org.uk/nhst/ay.htm
2006	NHS Working in Partnership Programme (WiPP)	To create stories with patients and staff celebrating the benefits of working together in creative and enlightened ways	www.patientvoices.org.uk/wipp.htm
2006	North East Yorkshire and North Lincolnshire Strategic Health Authority	To work with small teams to develop stories that provide insight into collaborative and interprofessional working for a range of conditions across the SHA	www.patientvoices.org.uk/neynl.htm
2013	North Middlesex University Hospital NHS Foundation Trust	To create stories with mothers and midwives about maternity services provided by the Trust in the hope of identifying opportunities for improvement	www.patientvoices.org.uk/nmx.htm
2012	Norwegian Museum of Science and Technology	To teach museum staff the Patient Voices reflective digital storytelling methodology using iPads and explore with them ways in which they might use the process and the stories	Stories created for internal use and learning for staff
2013	Oslo and Akershus University College of Applied Sciences	To teach the Patient Voices reflective digital storytelling methodology to academic staff working in healthcare and explore with them ways in which they might use the process and the stories	Stories created for internal use and learning for staff
2012	Oslo City Museum	To deliver the keynote presentation about creating digital stories with people with dementia at the Meeting with Memories conference	www.patientvoices.org.uk/pdf/presentations/Meeting%20Memories%20Oslo%20Dec%202012.pdf
2009	Poor Servants of the Mother of God	To facilitate a workshop in which Sisters could experience and explore the benefits of reflective digital storytelling within their organisation	Stories created for internal use and learning for staff
2016	Princess Alexandra Hospital NHS Foundation Trust	To create stories with medical doctors, from newly qualified to very experienced in order illuminate their experiences and for use in education and training	Not yet complete

Year	Sponsor	Aims of project	Weblink
2010	RCN in collaboration with INTEL	To create digital stories about the success of a telehealth project for people with COPD living on a remote Scottish Island	www.patientvoices.org.uk/telehealth.htm
2007	RCN Professional Development Framework	To create stories offering insights into what RCN members really want from the organisation	www.patientvoices.org.uk/rcnpdf.htm
2007	RCN Quality Improvement Programme	To create digital stories about continence care in care homes to be incorporated into an e-learning resource	www.patientvoices.org.uk/rcnqip.htm
2015	Roffey Park Institute	To create stories with a range of staff (from the CEO to the man with learning disabilities who works in the kitchen) about the ways in which the organisation's values (such as compassion and the importance of community) play out in every day working life	www.patientvoices.org.uk/roffey.htm
2006	Saigei and Wexham Park Hospital	To create stories about patient care and patient safety as part of a larger improvement initiative	Stories created for internal use and learning for staff
2008	Saskatoon Health Authority	To create stories that would form part of the evaluation of a Live Well™ project undertaken with First Nation peoples in Saskatchewan	www.patientvoices.org.uk/sask.htm
2009	Sheffield City Council	To create stories to illuminate the experiences of people caring for family members affected by serious mental illness for use in training and to identify support needs	www.patientvoices.org.uk/shefffcc.htm
2011	Sheffield City Council	To create stories with people from BME communities to illuminate the experiences of people caring for family members affected by serious mental illness for use in training and to identify support needs	www.patientvoices.org.uk/shefffcc2.htm
2008	Sheffield Hallam University	Stories to provide insight into the lives of people affected by mental health issues as a means of engaging and involving service users and carers in the education of healthcare students	www.patientvoices.org.uk/shu.htm
2008	Society of the Holy Child Jesus	To create stories initially for use in promoting the society, contributing to recruitment strategy and for use in international convocations to reflect on and prompt discussions about values and vows	www.patientvoices.org.uk/shcj.htm
2008	Society of the Holy Child Jesus	To create stories with the community's most elderly sisters so that they could be preserved and also to reveal the importance of community and vocation to individual and collective wellbeing	www.patientvoices.org.uk/shcj.htm
2010	South Essex NHS Partnership Trust	To create stories of leadership from members of the Board	www.patientvoices.org.uk/sept.htm
2015	South London and the Maudsley NHS Foundation Trust	Part of the 'Power of Story' project which aims to gather the unique experiences, life stories and thoughts of service users, relatives, carers and staff: these stories were intended to illuminate the experiences of working and being cared for in a specialist care home for people with dementia	www.patientvoices.org.uk/pos.htm

Year	Sponsor	Aims of project	Weblink
2014	South Staffordshire and Shropshire NHS Foundation Trust	To create stories that provide insights into living with mental illness for use in training, patient engagement and Board meetings	www.patientvoices.org.uk/pd.htm
2015	South Staffordshire and Shropshire NHS Foundation Trust	To create stories that provide insights into living with dementia for use in training, patient engagement and Board meetings	www.patientvoices.org.uk/lwd.htm
2013	South Tees Hospitals NHS Foundation Trust	To create stories with staff that would help to provide closure on a very challenging time in the history of the ward – and to serve as prompts and tools in OD work	www.patientvoices.org.uk/ht.htm
2015	Swiss Development Corporation	To provide consultancy and additional facilitation on a large workshop with staff working in developing countries to create stories about their experiences, intended for use within the organisation	Stories created for internal use and training for staff
2013	Teeside University	Part of a research project exploring the use of digital storytelling as a way of teaching compassion to physiotherapists (due to the nature of the research, only one story was released)	www.patientvoices.org.uk/flv/0682pv384.htm
2011	The Health Foundation (Closing the Gap Programme)	To facilitate the creation of stories in the aftermath of the Francis Report into the failings at Mid Staffordshire Hospital to provide insights into the experiences of people who had gone through the official complaints process to inform the design and development of a new complaints process	www.patientvoices.org.uk/speakingup.htm
2014	UK Higher Education Academy	To create stories about experiences of interprofessional education	Stories created for internal use and training for staff
2011	University of Abertay	Stories to offer insights into living with dementia, to be incorporated into e-learning course intended to teach compassion and emotional intelligence	www.patientvoices.org.uk/dc.htm
2008	University of Colorado College of Nursing	To provide consultancy to StoryCenter as they explored the use of digital storytelling as a potential reflective methodology in healthcare education. The Nurstory project has continued to collect stories from nurses and nursing faculty.	http://milehighstories.com/?page_id=21 www.patientvoices.org.uk/flv/0369pv384.htm
2008	University of Huddersfield	To provide an opportunity for staff to experience the Patient Voices approach to digital storytelling and to serve as a team bonding activity	www.patientvoices.org.uk/uh.htm
2008	University of Leeds Medical School	To create digital stories about the experiences of people living with rheumatoid arthritis in order to inform the design and development of appropriate devices and services	www.patientvoices.org.uk/wr.htm

Year	Sponsor	Aims of project	Weblink
2008	University of Leeds Medical School	To create digital stories about living with persistent cough for use in education and training	www.patientvoices.org.uk/pcgr.htm
2008	University of Leicester Medical School	Digital storytelling as a means of teaching reflection to medical students	www.patientvoices.org.uk/lssc.htm
2009	University of Liverpool	To create stories about patient involvement and its benefits for use in teaching	www.patientvoices.org.uk/ul.htm
2016	University College London Hospitals NHS Foundation Trust	To create stories with clinicians working in the complex pain team, and some of their patients, for use in education and training and a second workshop with patients who have had treatment from the complex pain team	Not yet complete
2009	University of Nottingham School of Health Sciences	Storytelling with newly-qualified nurses as an opportunity to reflect on difficult experiences and to create stories for use in developing strategies to support future students	www.patientvoices.org.uk/un.htm
2010	University of Nottingham School of Health Sciences	Stories created by Allied Health Professionals to reflect the importance of interprofessional working, including with patients and carers	www.patientvoices.org.uk/unahp.htm
2010	University of Nottingham School of Education	To create stories with staff and students working in Nottingham and in Malaysia, to share experiences and promote international collaboration	www.patientvoices.org.uk/untesol.htm
2014	World Health Organisation and Grand Challenges Canada	To create stories with parents of children suffering brain damage from malaria to communicate results of a ten-year research study into a new drug	www.patientvoices.org.uk/savingbrains.htm

Appendix 2: Contribution to publications

The following table shows the contribution I have made to each of the publications included in this thesis.

RDPUB forms, confirming my contribution to the papers and signed by the other authors are included on the following pages.

Year of publication	Title of publication	Authors	% contribution
2011	Tell me a story: a conceptual exploration of storytelling in healthcare	Carol Haigh and Pip Hardy	40
2011	Challenging the shock of reality through digital storytelling	Gemma Stacey and Pip Hardy	30
2012	Dangling conversations: reflections on the process of creating digital stories with people with early stage dementia	Rosie Stenhouse, Jo Tait, Pip Hardy and Tony Sumner	25
2014	Our stories ourselves: exploring identities, sharing experiences and building relationships through Patient Voices	Pip Hardy and Tony Sumner	75
2014	The journey begins	Pip Hardy	100
2015	First do no harm: developing an ethical process of consent and release for digital storytelling in healthcare	Pip Hardy	100
2017	Physician know thyself: digital storytelling with medical students	Pip Hardy	100
2017	Digital storytelling with users and survivors of the UK mental health system	Pip Hardy and Tony Sumner	90

Research and Knowledge Exchange

Graduate School

Form RDPUB (ROUTE 1 AND 2)



PhD BY PUBLISHED WORK (ROUTE 1/2): CONTRIBUTION TO PUBLICATIONS

This form is to accompany an application for registration for PhD where the PhD is by Published Work. A separate form should be completed for each publication that is submitted with the proposal and should accompany the RD1 form.

1. The Candidate

First Name(s):	Victoria	Preferred Title:	Ms
Surname:	Hardy		
MMU e-mail address:		Contact Number:	07721 751784
Personal e-mail address:	pip@pilgrimprojects.co.uk	Student ID Number:	11503117

2. Title of PhD Proposal

Telling tales: an investigation into the creation and use of digital stories and digital storytelling to transform culture in health and social care organisations

Title of Research Output

Tell me a story: a conceptual exploration of storytelling in healthcare education

3. Candidate's contribution to the research output

(State nature and approximate percentage contribution of each author)

Approximately 40% of the paper was written by the candidate.

4. Co author(s):

I confirm that the contribution indicated above is an accurate assessment of the contribution by the candidate to the research output named in section 3.

Name	Signature	Current e-mail address
Carol Haigh		c.haigh@mmu.ac.uk

5. Statement by Director of Studies/Advisor

I confirm that I have read the above publication and am satisfied that the extent and nature of the candidate's contribution is as indicated in section 4 above.

Signature:		Date:	08/08/16
	(Director of Studies/Advisor)		

RDPUB, version 1.0, 22/08/2014

**Research and Knowledge Exchange
Graduate School
Form RDPUB (ROUTE 1 AND 2)**



**PhD BY PUBLISHED WORK (ROUTE 1/2):
CONTRIBUTION TO PUBLICATIONS**

This form is to accompany an application for registration for PhD where the PhD is by Published Work. A separate form should be completed for each publication that is submitted with the proposal and should accompany the RD1 form.

1. The Candidate

First Name(s):	Victoria	Preferred Title:	Ms
Surname:	Hardy		
MMU e-mail address:		Contact Number:	07721 751784
Personal e-mail address:	pip@pilgrimprojects.co.uk	Student ID Number:	11503117

2. Title of PhD Proposal

Telling tales: an investigation into the creation and use of digital stories and digital storytelling to transform culture in health and social care organisations

Title of Research Output

Challenging the shock of reality by digital storytelling

3. Candidate's contribution to the research output

(State nature and approximate percentage contribution of each author)

Approximately 30% of the paper was written by the candidate.

4. Co author(s):

I confirm that the contribution indicated above is an accurate assessment of the contribution by the candidate to the research output named in section 3.

Name	Signature	Current e-mail address
Gemma Stacey		Gemma.stacey@nottingham.ac.uk

5. Statement by Director of Studies/Advisor

I confirm that I have read the above publication and am satisfied that the extent and nature of the candidate's contribution is as indicated in section 4 above.

Signature:		Date:	
	(Director of Studies/Advisor)		

6. Signature of Faculty Research Degrees Administrator

Signature:		Date:	
	(Faculty Research Degrees Administrator)		

RDPUB, version 1.0, 22/08/2014

Research and Knowledge Exchange

Graduate School

Form RDPUB (ROUTE 1 AND 2)



PhD BY PUBLISHED WORK (ROUTE 1/2): CONTRIBUTION TO PUBLICATIONS

This form is to accompany an application for registration for PhD where the PhD is by Published Work. A separate form should be completed for each publication that is submitted with the proposal and should accompany the RD1 form.

1. The Candidate

First Name(s):	Victoria	Preferred Title:	Ms
Surname:	Hardy		
MMU e-mail address:		Contact Number:	07721 751784
Personal e-mail address:	pip@pilgrimprojects.co.uk	Student ID Number:	11503117

2. Title of PhD Proposal

Telling tales: an investigation into the creation and use of digital stories and digital storytelling to transform culture in health and social care organisations

Title of Research Output

Our stories ourselves: exploring identities, sharing experiences and building relationships through Patient Voices

3. Candidate's contribution to the research output

(State nature and approximate percentage contribution of each author)

Approximately 75% of the paper was written by the candidate.

4. Co author(s):

I confirm that the contribution indicated above is an accurate assessment of the contribution by the candidate to the research output named in section 3.

Name	Signature	Current e-mail address
Tony Sumner		tony@pilgrimprojects.co.uk

5. Statement by Director of Studies/Advisor

I confirm that I have read the above publication and am satisfied that the extent and nature of the candidate's contribution is as indicated in section 4 above.

Signature:		Date:	
	(Director of Studies/Advisor)		

6. Signature of Faculty Research Degrees Administrator

Signature:		Date:	
	(Faculty Research Degrees Administrator)		

RDPUB, version 1.0, 22/08/2014

**Research and Knowledge Exchange
Graduate School
Form RDPUB (ROUTE 1 AND 2)**



**PhD BY PUBLISHED WORK (ROUTE 1/2):
CONTRIBUTION TO PUBLICATIONS**

This form is to accompany an application for registration for PhD where the PhD is by Published Work. A separate form should be completed for each publication that is submitted with the proposal and should accompany the RD1 form.

1. The Candidate

First Name(s):	Victoria	Preferred Title:	Ms
Surname:	Hardy		
MMU e-mail address:		Contact Number:	07721 751784
Personal e-mail address:	pip@pilgrimprojects.co.uk	Student ID Number:	11503117

2. Title of PhD Proposal

Telling tales: an investigation into the creation and use of digital stories and digital storytelling to transform culture in health and social care organisations

Title of Research Output

Digital storytelling with users and survivors of the UK mental health system

3. Candidate's contribution to the research output

(State nature and approximate percentage contribution of each author)

Approximately 90% of the paper was written by the candidate.

4. Co author(s):

I confirm that the contribution indicated above is an accurate assessment of the contribution by the candidate to the research output named in section 3.

Name	Signature	Current e-mail address
Tony Sumner		tonhy@pilgrimprojects.co.uk

5. Statement by Director of Studies/Advisor

I confirm that I have read the above publication and am satisfied that the extent and nature of the candidate's contribution is as indicated in section 4 above.

Signature:		Date:	
	(Director of Studies/Advisor)		

6. Signature of Faculty Research Degrees Administrator

Signature:		Date:	
	(Faculty Research Degrees Administrator)		

RDPUB, version 1.0, 22/08/2014

This form is to accompany an application for registration for PhD where the PhD is by Published Work. A separate form should be completed for each publication that is submitted with the proposal and should accompany the RD1 form.

1. The Candidate

First Name(s):	Victoria	Preferred Title:	Ms
Surname:	Hardy		
MMU e-mail address:		Contact Number:	07721 751784
Personal e-mail address:	pip@pilgrimprojects.co.uk	Student ID Number:	11503117

2. Title of PhD Proposal

Telling tales: an investigation into the creation and use of digital stories and digital storytelling to transform culture in health and social care organisations

Title of Research Output

Dangling conversations: reflections on the process of creating digital stories during a workshop with people with early-stage dementia


3. Candidate's contribution to the research output

(State nature and approximate percentage contribution of each author)

Approximately 25% of the paper was written by the candidate.

4. Co author(s):

I confirm that the contribution indicated above is an accurate assessment of the contribution by the candidate to the research output named in section 3.

Name	Signature	Current e-mail address
Rosie Stenhouse		
Jo Tait		jotait1@mac.com
Tony Sumner		

5. Statement by Director of Studies/Advisor

I confirm that I have read the above publication and am satisfied that the extent and nature of the candidate's contribution is as indicated in section 4 above.

Signature:		Date:	
	(Director of Studies/Advisor)		

6. Signature of Faculty Research Degrees Administrator

Signature:		Date:	
	(Faculty Research Degrees Administrator)		

ROPUB, version: 1.0, 22/08/2014

Research and Knowledge Exchange

Graduate School

Form RDPUB (ROUTE 1 AND 2)



PhD BY PUBLISHED WORK (ROUTE 1/2): CONTRIBUTION TO PUBLICATIONS

This form is to accompany an application for registration for PhD where the PhD is by Published Work. A separate form should be completed for each publication that is submitted with the proposal and should accompany the RD1 form.

1. The Candidate

First Name(s):	Victoria	Preferred Title:	Ms
Surname:	Hardy		
MMU e-mail address:		Contact Number:	07721 751784
Personal e-mail address:	pip@pilgrimprojects.co.uk	Student ID Number:	11503117

2. Title of PhD Proposal

Telling tales: an investigation into the creation and use of digital stories and digital storytelling to transform culture in health and social care organisations

Title of Research Output

Dangling conversations: reflections on the process of creating digital stories during a workshop with people with early-stage dementia

3. Candidate's contribution to the research output

(State nature and approximate percentage contribution of each author)

Approximately 25% of the paper was written by the candidate.

4. Co author(s):

I confirm that the contribution indicated above is an accurate assessment of the contribution by the candidate to the research output named in section 3.

Name	Signature	Current e-mail address
Rosie Stenhouse		Rosie.Stenhouse@ed.ac.uk
Jo Tait		
Tony Sumner		tony@pilgrimprojects.co.uk

5. Statement by Director of Studies/Advisor

I confirm that I have read the above publication and am satisfied that the extent and nature of the candidate's contribution is as indicated in section 4 above.

Signature:		Date:	
	(Director of Studies/Advisor)		

6. Signature of Faculty Research Degrees Administrator

Signature:		Date:	
	(Faculty Research Degrees Administrator)		

RDPUB, version 1.0, 22/08/2014

Appendix 3: Contracts for publications in press

Consent to Publish

Series Title:

Digital Education and Learning

Published under the imprint

Palgrave Macmillan

Title of Book/Volume/Conference: Digital Storytelling in Higher Education - International Perspectives

Editor(s) name(s): Yngve Nordkvelle, Pip Hardy, Heather Pleasants and Grete Jamissen

Title of Contribution: Physician, know thyself: using digital storytelling to promote reflection in medical education

Author(s) full name(s): Pip Hardy

Corresponding Author's name, address, affiliation and e-mail: Pip Hardy, 91 Waterbeach Road, Landbeach, Cambridge CB25 9FA UK; Co-founder, Patient Voices Programme.
pip@pilgrimprojects.co.uk

When Author is more than one person the expression "Author" as used in this agreement will apply collectively unless otherwise indicated.

§ 1 Rights Granted

Author hereby grants to **Springer International Publishing AG** (hereinafter called Publisher) the exclusive, sole, permanent, world-wide, transferable, sub-licensable and unlimited right to reproduce, publish, distribute, transmit, make available or otherwise communicate to the public, translate, publicly perform, archive, store, lease or lend and sell the Contribution or parts thereof individually or together with other works in any language, in all revisions and versions (including soft cover, book club and collected editions, anthologies, advance printing, reprints or print to order, microfilm editions, audiograms and videograms), in all forms and media of expression including in electronic form (including offline and online use, push or pull technologies, use in databases and data networks (e.g. the Internet) for display, print and storing on any and all stationary or portable end-user devices, e.g. text readers, audio, video or interactive devices, and for use in multimedia or interactive versions as well as for the display or transmission of the Contribution or parts thereof in data networks or search engines, and posting the Contribution on social media accounts closely related to the Work), in whole, in part or in abridged form, in each case as now known or developed in the future, including the right to grant further time-limited or permanent rights. Publisher especially has the right to permit others to use individual illustrations, tables or text quotations and may use the Contribution for advertising purposes. For the purposes of use in electronic forms, Publisher may adjust the Contribution to the respective form of use and include links (e.g. frames or inline-links) or otherwise combine it with other works and/or remove links or combinations with other works provided in the Contribution. For the avoidance of doubt, all provisions of this contract apply regardless of whether the Contribution and/or the Work itself constitutes a database under applicable copyright laws or not.

The copyright in the Contribution shall be vested in the name of Author. Author has asserted his/her right(s) to be identified as the originator of this Contribution in all editions and versions of the Work and parts thereof, published in all forms and media. Publisher may take, either in its own name or in that of Author, any necessary steps to protect the rights granted under this Agreement against infringement by third parties. It will have a copyright notice inserted into all editions of the Work according to the provisions of the Universal Copyright Convention (UCC).

The parties acknowledge that there may be no basis for claim of copyright in the United States to a Contribution prepared by an officer or employee of the United States government as part of that person's official duties. If the Contribution was performed under a United States government contract, but Author is not a United States government employee, Publisher grants the United States government royalty-free permission to reproduce all or part of the Contribution and to authorise others to do so for United States government purposes. If the Contribution was prepared or published by or under the direction or control of Her Majesty (i.e., the constitutional monarch of the Commonwealth realm) or any Crown government department, the copyright in the Contribution shall, subject to any agreement with Author, belong to Her Majesty. If Author is

an officer or employee of the United States government or of the Crown, reference will be made to this status on the signature page.

§ 2 Rights retained by Author

Author retains the following re-use rights, without the requirement to seek additional formal permission from Publisher:

- a) to re-use excerpts of the material in new works, if the new work is authored or edited by Author, and provided such new works are not of a nature likely to compete with the Work (if Author is not the author or editor of the new work, the publisher of the new work shall be asked to submit a permission request to Publisher);
- b) to re-use figures, illustrations and tables from the Contribution (provided that these are not 3rd party material, in which case additional permission will need to be sought from the rights-holder) in new works authored or edited by Author;
- c) to make copies of the Contribution for personal use, including up to one chapter for classroom teaching use (but not for inclusion in course pack material for onward sale by libraries and institutions);
- d) to make and distribute a reasonable number of copies of the Contribution to selected colleagues for their personal use, but not for commercial or systematic distribution;
- e) to make print or digital copies of the Contribution to append to a Curriculum Vitae in support of applications for new posts;
- f) if the Contribution is made within the scope of Author's employment, the Author's employer may use all or part of the Contribution for other intra-company use (e.g. training);
- g) to post the pre-copy-edited Contribution on Author's own web sites, or institutional repositories, or Author's funding body(s)' archive, after an embargo period of 36 months after publication of the printed or online edition of the Work. Any linking, collection or aggregation of chapters from the same volume is strictly prohibited.

Any such re-use of the Contribution or parts of it is subject to acknowledgement of the original publication in the following form:

[author of the contribution], [contribution title] published in [book title] edited by [editor of the book], [year of publication], [publisher (as it appears on the cover of the book)] reproduced with permission of [publisher (as it appears on the copyright page of the book)].

§ 3 Warranties

Author agrees, at the request of Publisher, to execute all documents and do all things reasonably required by Publisher in order to confer to Publisher all rights intended to be granted under this Agreement. Author warrants that the Contribution is original except for such excerpts from copyrighted works (including illustrations, tables, animations and text quotations) as may be included with the permission of the copyright holder thereof, in which case(s) Author is required to obtain written permission to the extent necessary and to indicate the precise sources of the excerpts in the manuscript. Third Party Material (including without limitation quotations, photographs, pictures, diagrams, drawings, tables, graphs or maps, and whether reproduced from print or electronic or other sources) may only be included in the Contribution: (a) with the prior agreement of the Publisher, and (b) Publisher agrees to the inclusion of any Third Party Material in the Contribution. In this case the Author must obtain (at the Author's expense) all necessary permissions to enable the Publisher to use the Third Party Material in the Contribution and shall provide the Editor of the Work and the Publisher with: (i) copies of all such permissions, and (ii) sufficient information to enable the Publisher to make appropriate acknowledgements.

Author warrants that Author is entitled to grant the rights in accordance with Clause 1 "Rights Granted", that Author has not assigned such rights to third parties, that the Contribution has not heretofore been published in whole or in part, that the Contribution contains no libellous or defamatory statements and does not infringe on any copyright, trademark, patent, statutory right or proprietary right of others, including rights obtained through licences; and that Author will indemnify Publisher against any costs, expenses or damages for which Publisher may become liable as a result of any claim which, if true, would constitute a breach by Author of any of Author's representations or warranties in this Agreement.

Author agrees to amend the Contribution to remove any potential obscenity, defamation, libel, malicious falsehood or otherwise unlawful part(s) identified at any time. Any such removal or alteration shall not affect the warranty and indemnity given by Author in this Agreement.

§ 4 Delivery of Contribution and Publication

Author shall deliver the Contribution to the responsible Editor on a date to be agreed upon, electronically in Microsoft Word format or in such form as may be agreed in writing with Publisher. The Contribution shall be in

a form acceptable to the Publisher (acting reasonably) and in line with the instructions contained in the guidelines and Author shall provide at the same time, or earlier if the Publisher reasonably requests, any editorial, publicity or other form required by the Publisher.

Publisher will undertake the publication and distribution of the Work in print and electronic form at its own expense and risk within a reasonable time after it has given notice of its acceptance of the Work to Author in writing.

§ 5 Author's Discount for Books and Electronic Access

Author may obtain copies of the Work for personal use at a discount of 40% off the list-price if ordered directly from Publisher. Furthermore, Author is entitled to purchase for his/her personal use (directly from Publisher) other books published by Publisher at a discount of 40% off the list price for as long as there is a contractual arrangement between Author and Publisher and subject to applicable book price regulation. Resale of such copies is not permitted.

Publisher shall provide electronic access to the electronic final published version of the Work on Publisher's Internet portal, currently known as SpringerLink, to Author. Furthermore, Author has the right to download and disseminate single chapters from the electronic final published version of the Work for his/her private and professional non-commercial research and classroom use (e.g. sharing the chapter by mail or in hard copy form with research colleagues for their professional non-commercial research and classroom use, or to use it for presentations or handouts for students). Author is also entitled to use single chapters for the further development of his/her scientific career (e.g. by copying and attaching chapters to an electronic or hard copy job or grant application).

When Author is more than one person each of the co-authors may share single chapters of the Work with other scientists as described above. In each case, Publisher grants the rights to Author under this clause provided that Author has obtained the prior consent of any co-author(s) of the respective chapter.

§ 6 Termination

Either party shall be entitled to terminate this Agreement forthwith by notice in writing to the other party if the other party commits a material breach of the terms of the Agreement which cannot be remedied or, if such breach can be remedied, fails to remedy such breach within 28 days of being given written notice to do so. On termination of this Agreement in accordance with its terms, all rights and obligations of Publisher and Author under this Agreement will cease immediately, except that any terms of this Agreement that expressly or by implication survive termination of this Agreement shall remain in full force and effect.

§ 7 Governing Law and Jurisdiction

If any difference shall arise between Author and Publisher concerning the meaning of this Agreement or the rights and liabilities of the parties, the parties shall engage in good faith discussions to attempt to seek a mutually satisfactory resolution of the dispute. This agreement shall be governed by, and shall be construed in accordance with, the laws of Switzerland. The courts of Zug, Switzerland shall have the exclusive jurisdiction.

Corresponding Author signs for and accepts responsibility for releasing this material on behalf of any and all Co-Authors.

Signature of Corresponding Author:

Date:

Pip Hardy

23rd August 2016

- ☐ I'm an employee of the US Government and transfer the rights to the extent transferable (Title 17 §105 U.S.C. applies)
☐ I'm an employee of the Crown and copyright on the Contribution belongs to Her Majesty

For internal use only:

Order Number:

GPU/PD/PS:

Legal Entity Number: 1128 Springer International Publishing AG

Palgrave-C-CTP-05/2016

CONTRIBUTOR AGREEMENT

Title of the Contribution: (the "Contribution")

Digital storytelling with service users and survivors of the UK mental health system

Title of Work: (the "Work")

Story, Form and Content in Digital Storytelling: Telling Tales

Fee (Only if applicable): (the "Fee")

Author(s): if more than one author list by Author 1, 2, etc (the "Author")

Pip Hardy

Tony Sumner

Editor(s): (the "Editor")

Mark Dunford and Tricia Jenkins

To: Palgrave Macmillan, a division of Macmillan Publishers Ltd (The "Publisher")

1. In consideration of the Editor evaluating the Contribution with a view to its inclusion in the Work and/or payment by the Publisher to the Author of the Fee (if applicable) upon delivery by the Editor and acceptance by the Publisher of a final typescript of the Work and one complimentary copy of the Work to be delivered to the Author on publication by the Publisher, the Author grants to the Publisher for the full term of copyright and any extensions thereto, the exclusive right and licence:

- to edit, adapt, publish, reproduce, distribute, display and store the Contribution including without limitation any associated tables, graphs and images in all forms, formats and media whether now known or hereafter developed (including without limitation in print, digital and electronic form) throughout the world; and
- to translate the Contribution into other languages, create adaptations, summaries or extracts of the Contribution or other derivative works based on the Contribution and exercise all of the rights set out in (a) above in such translations, adaptations, summaries, extracts and derivative works; and
- to license others to do any or all of the above.

2. Ownership of copyright remains with the Author, and provided that, when reproducing the Contribution or extracts from it, the Author acknowledges and references first publication in the Work, the Author retains only the following non-exclusive rights:

- to re-use excerpts or up to one chapter of the Contribution in new works, if the new work is authored or edited by the Author and provided such new works are not of a nature likely to compete with the Palgrave Macmillan Work.
- if the Contribution is made within the scope of the Author's employment, they may use all or part of the Contribution for other intra-company use such as training.
- to make copies of the Contribution for personal use, including up to one chapter for classroom teaching use (but not for inclusion in course pack material for onward sale by libraries and institutions). To make and distribute a reasonable number of copies of the Contribution to selected colleagues for their personal use, but not for commercial or systematic distribution. Make print or digital copies of the Contribution to append to the Author's Curriculum Vitae in support of applications for new posts.
- to post up to one chapter of the pre-copy-edited Contribution for single authored works on the Author's own web sites, or institutional repositories, or the Author's funding body's archive, thirty six months after publication of the printed or online edition of the Work, provided that they also acknowledge Palgrave Macmillan. For single authored works or for contributed volumes: each contributor may archive up to one chapter per volume (provided they are the author or a co-author of such chapter). Please note that any linking, collection or aggregation of chapters from the same volume is strictly prohibited; and
- to re-use figures, illustrations and tables from the Contribution created by the Author in new works authored or edited by them.

3. The Author hereby warrants and represents that:

- the Author is the sole author of and sole owner of the copyright in the Contribution and all material comprised in it and that the Contribution is the original work of the Author and not copied (in whole or part) from another work. If however the Contribution

includes materials from other sources, the Author warrants that the Author has obtained the permission of the owners of the copyright in all such materials to enable the grant of rights contained herein and shall supply copies of all such permissions attached to this Agreement; and

- all of the facts contained in the Contribution are true and accurate; and
- The Author has the full right, power and authority to enter into this Agreement; and
- nothing in the Contribution is obscene, defamatory, libellous, violates any right of privacy or publicity, pirates or plagiarizes any other work, or infringes any intellectual property rights (including without limitation copyright, patent or trademark) or any other rights of any kind of any person or entity or is otherwise unlawful; and
- nothing in the Contribution infringes any duty of confidentiality which the Author may owe to anyone else including without limitation any institution in which work recorded in the Contribution was carried out or violates any contract, express or implied, of the Author.

The Authors agree to keep the Publisher, its assigns and licensees indemnified at all times against all losses actions, claims, proceedings, costs and damages arising out of any breach or alleged breach of any of the warranties above.

4. The Author authorises the Publisher to take such steps as it considers necessary at its own expense in the Author's name and on their behalf if the Publisher believes that a third party is infringing or is likely to infringe copyright in the Contribution including but not limited to initiating legal proceedings.

5. The Author hereby asserts to the Publisher and the Publisher's licensees the Author's moral right of paternity in the Contribution. The Author irrevocably and unconditionally waives the Author's moral right as provided in the Copyright, Designs and Patents Act 1988 to the extent the Publisher reasonably deems necessary to allow the Publisher to exercise and license the rights granted to the Publisher under this Agreement.

6. The Author shall cooperate fully with the Publisher in relation to any legal action that might arise from the publication of the Contribution and the Author shall give the Publisher access at reasonable times to any relevant accounts, documents and records within the power or control of the Author.

7. The Editor shall have the right to make or to request the Author to make any revision to the Contribution which the Editor may deem necessary and to decide as to the inclusion or omission of the Contribution in/from the Work.

8. Nothing in this Agreement shall oblige or require the Publisher to publish the Contribution now or at any future time. If the Publisher does not publish the Contribution the Publisher shall revert all rights under this Agreement to the Author.

9. The parties agree that this Agreement (a) shall be governed by and construed in accordance with the laws of England and Wales and that the courts of England and Wales shall have exclusive jurisdiction to settle any dispute or claim that arises out of or in connection with it and (b) contains the entire agreement and understanding of the parties with respect to its subject matter and supersedes all prior agreements written or oral and each of the parties acknowledges and (c) that no variation to this agreement shall be effective unless it is in writing and signed by or on behalf of both parties.

(PLEASE NOTE, ONLY HAND WRITTEN SIGNATURES ARE ACCEPTED)

Signed by Author 1:

Pip Hardy

Signed by Author 2:

Tony Sumner

Signed by Author 3:

Signed by Author 4:

Signed by Author 5:

Print name:

Pip Hardy

Print name:

Tony Sumner

Print name:

Print name:

Print name:

Date:

29 February 2016

Date:

29/2/16

Date:

Date:

Date:

Does the Contribution contain material from third parties (including previously published material)? Yes ☐ No ☒ (if yes, please ensure copies of the permissions are submitted with this form as indicated in clause 3 (a))